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Title:
"We are normal, we just have a different wiring"

A narrative inquiry into the identity and sense-making of adolescent autistic girls

“We are normal, we just have a different wiring”: A narrative inquiry into the identity and sense-making of adolescent autistic girls

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A dissertation submitted to the University of Bristol in accordance with the requirements for award of the degree of Doctorate in Educational Psychology (DEdPsy) in the Faculty of Policy studies.

4th September 2020

Word count: 45, 203

Abstract

Autistic females are often reported as being undiagnosed, misdiagnosed or diagnosed late. Although there has been a recent increasing interest in autistic females, much research aims to operationalise the 'female autistic profile'. There is a lack of exploration to understand what this often identity changing, but male-biased diagnosis means for autistic females' identity and sense-making.

This research aims to understand what adolescent autistic girls' narratives indicate about how they make sense of and identify with their autism. As a key time for identity formation, adolescence was the focus (Erikson, 1968). Secondly, this research aims to understand the significant relationships and experiences that influenced participants' identification with their autism.

Five adolescent autistic girls were invited to reflect upon their experience of autism. Their narratives were collected during interviews and analysed using Narrative Oriented Inquiry. Participants were provided with visuals and options for their interviews to support their engagement and comfort.

Participants' narratives highlighted the complex and heterogeneous nature of their constructs of autism. There were some similarities, but also noticeable differences due to their varied experiences. It seemed important for all participants to have had opportunities to explore their autism diagnosis in a supportive and accepting environment, before committing to it. Their self-understanding and being understood by others were integral. Participants needed to experience belonging and reassurance in their families, friendships and schools to conceptualise autism as a difference recognising both the challenges and the positives, instead of a disability.

Implications arose that are relevant for everyone interacting with autistic girls, additionally to specific implications for Educational Psychologists. For autistic girls' success in a learning environment, person-centred planning is needed. Furthermore, the importance of Educational Psychologists remaining reflexive and examining their own understanding and assumptions of autistic girls is essential.

Author’s Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's *Regulations and Code of Practice for Research Degree Programmes* and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

Signed …… Date ……..

Dedication

For my Mum and Dad, my constant source of encouragement and support.

Acknowledgements

I would like to thank the following people for their support and encouragement throughout this process. Without them, this dissertation would not have been possible.

Firstly, thank you to the five young people who took part, it was truly a privilege to hear and share your stories. Your engagement and openness throughout have made it possible to make this dissertation what it is.

Thank you to my wonderful family, partner and friends who have constantly encouraged me and believed in me throughout my doctorate, even when I've struggled to myself. A special thanks to all those who were interested in my research and those who were kind enough to proofread a chapter or two for me.

To my nine other course mates, I feel honoured to have been through these three years with you all, you are fantastic and such an amazing bunch of people.

To my placement supervisor Dr Sarah Green, and the whole of my Educational Psychology Service, thank you for your wealth of knowledge and support throughout my time with you. I am excited to embark on my career as a qualified Educational Psychologist with you.

Finally, thank you to all the tutors at Bristol, but especially Dr Rob Green and Dr Amanda Gaulter who have offered great guidance and advice as supervisors throughout this dissertation process. This course has been truly transformative, which has only been possible through the support and knowledge you have all shared.

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List of Acronyms

AQ – Autistic Quotient

ASD – Autism Spectrum Disorder

BPS – British Psychological Society

CBT – Cognitive Behavioural Therapy

DSM – Diagnostic and Statistical Manual of Mental Disorders

EP – Educational Psychologist

GCSEs – General Certificate of Secondary Education

ICD – International Classification of Diseases

IPA – Interpretative Phenomenological Analysis

IQ – Intelligence Quotient

LA – Local Authority

NI – Narrative Inquiry

NOI – Narrative Oriented Inquiry

PDA – Pathological Demand Avoidance

RE – Religious Education

SENCo – Special Educational Needs Co-ordinator

SEND – Special Educational Needs and Disability

TA – Teaching Assistant

TEP – Trainee Educational Psychologist

UNCRC – United Nations Convention on the Rights of the Child

UNICEF – United Nations Children's Fund

1 Introduction

This research was conducted in partial fulfilment of an Educational Psychology Doctorate at the University of Bristol. In years two and three I completed a placement and conducted my research within a Midlands-based local authority (LA).

This chapter will cover the context of my research, enabling understanding of this dissertation's origins. The rationale behind the language and terminology used will first be explained. Then, personal and professional motivations will be discussed before outlining the research context. The current understanding of autism will also be explored and the research aims identified. Finally, the structure of this dissertation is outlined.

1.1 Introducing This Research

There is an increasing interest and awareness of autistic females; it is reported they are often undiagnosed, misdiagnosed or diagnosed late (Gould, 2017). It is unfortunate that receiving a diagnosis commonly follows a mental health crisis, very often anxiety, depression or an eating disorder (Lai et al., 2015; Rynkiewicz & Łucka, 2018). Although there are debates about the utility of receiving an autism diagnosis (Begon & Billington, 2019) this is not the focus of this research. Instead, this study is exploring the identity and sense-making of autistic girls using a narrative methodology, based upon a relativist ontological perspective. By using this approach, influential experiences and relationships upon participants' understanding and construction of their autism will be highlighted.

1.2 A Note on Language

Throughout this dissertation I will be using the term 'autistic female' as opposed to 'female with autism'. This is in response to research that has indicated that the majority of, although not all, autistic individuals prefer identity-first language (Gernsbacher, 2017; Kapp et al., 2013; Kenny et al., 2016). Therefore, the language used reflects the most common preference of the Autistic Community. Nevertheless, in future chapters when discussing individual participants, I will use their preferred language to ensure they are addressed how they wish to be.

Furthermore, I will use the terms 'girl', 'female' and 'woman' to describe different cohorts. For transparency and practicality, I will use 'female' when it is a comment relating to all females regardless of age. If 'girl' is used this indicates a female under 18 years old; if 'woman' is used, this is an adult female.

Additionally, it may be noticed that I refrain from using the term 'neurotypical' and instead use 'non-autistic'. This is through being true to my Critical Autism perspective whereby I understand autism as a variation of human development as opposed to a separate category deviating from 'neurotypical', as the next section will explain.

1.3 Motivation for This Research

For any narrative research it is important to recognise that the researcher brings their own personal context that will influence the research (Riessman, 2008). Therefore, in the interest of transparency and reflexivity, I will briefly discuss my personal and professional motivation for this dissertation.

This research has resulted from a long-standing personal interest in autism. Over the years I have worked with many autistic young people in various roles within schools such as teaching assistant, therapy assistant, assistant Special Educational Needs Coordinator (SENCo) and now as a Trainee Educational Psychologist (TEP). As a psychology undergraduate, I completed a placement year within an autism provision, which led to my undergraduate dissertation exploring the visual acuity of autistic males. It was during this year that my interest specifically in autistic females was sparked. The school was traditionally male-only, however, that year, a female was enrolled. I began to wonder what being the only girl in the school must feel like, and what impact it would have on her, and her developing identity. Since, I have met and worked with many other autistic girls and have always been interested in how they make sense of their diagnosis.

This interest in autistic females and their relationship with their diagnosis has become more prevalent for me as a TEP when exploring the evidence-base for supporting autistic females. It is noticeable to myself how my understanding of autism has evolved over the years moving from an essentialist perspective, towards a more relativist understanding; appreciating that each individual's experience of autism is unique. I noted in my reflection diary kept throughout this research: "*as a practitioner, I am trying to adopt the critical approach to autism, however I was previously embedded in the deficit-orientated, and currently am in the process of shifting my discourse and vocabulary*". Therefore, as my perspective of autism is changing, I would like to be more informed by the individuals that experience it themselves. Consequently, this dissertation is not seeking to 'uncover' the one unifying autistic female identity and experience, rather it is exploring and exemplifying the range of experiences whilst developing an appreciation for the different understanding and constructions of autism from the people most concerned.

Professionally, autism is a significant element to a lot of Educational Psychologists' (EPs) work (Gilling, 2012). Therefore, it is important for practitioners to uncover young people's individual understanding and construction of their autism to be most effective. It feels important to understand what factors may influence their relationship with their diagnosis to have more insight into what can be supportive, and what is not. This dissertation is embedded in these personal beliefs and professional motivation, aiming to raise awareness and perhaps challenge some of the stereotypes from the current autism discourse. Additionally, this research aims to enable practitioners to critically question their current understanding, as I have done myself throughout. Therefore, I invite readers to also remain open to their preconceived ideas of autistic females being challenged throughout this dissertation. My reflexive practices have been key to understanding the impact on my personal construction of autism.

1.4 Research Context

Historically, autism has been considered a male diagnosis; a common gender ratio cited has been four males to one female (Fombonne, 2009). Yet, with the increasing profile of autistic females within literature but also within society, this gender gap is decreasing. More recent statistics estimate the gender ratio to be closer to three males to every female (Loomes et al., 2017). However, there is a continuing sense that autistic females are still "understudied, under identified, misdiagnosed and misunderstood" (Haney & Cullen, 2017, p.58).

This male-bias is further perpetuated due to most autistic research participants being male, reinforcing the male stereotype (Milner et al., 2019). However, some research suggests that females present differently (Lai et al., 2015), and gendered societal expectations may influence how each relate to their diagnoses; for example, by influencing their motivation to hide autistic traits (Kock, et al., 2019). As such, specifically how females experience autism needs to be explored, as many autistic women feel distanced from the male autistic stereotypes (Davidson, 2007). With greater awareness, more females may be recognised as needing support (which is not inextricably linked to diagnosis) and may access that support earlier (Baldwin & Costley, 2016).

It is an unfortunate truth that females have often faced adverse experiences before receiving an autism diagnosis (Baldwin & Costley, 2016; Bargiela et al., 2016; Hull et al., 2017; Milner et al., 2019; Zener, 2019). They are more likely than both autistic males and non-autistic females to have experienced an internalising pathology such as an eating disorder, anxiety disorder, school phobia, social anxiety, gender dysphoria or experienced being thought of as odd or eccentric by

peers (Lai et al., 2015). It is often in their early teenage years that they are diagnosed with autism; a label associated with boys (Cridland et al., 2014) and often perceived with negative stereotypes and being 'weird' (Treweek et al., 2019). It may be especially difficult when receiving this diagnosis during adolescence, a crucial time for identity formation (Erikson, 1968).

More research is being published about autistic females (Tierney et al., 2016) and anecdotally, there is increasing interest and awareness throughout the school systems. However, much of the research conducted has aimed to describe the female autistic profile regarding cognitive ability and functioning from a personal-deficit model of autism (Begon & Billington, 2019; Cook et al., 2018). Research into qualitative experiences is recognised as missing (Baldwin & Costley, 2016; Kirkovski et al., 2013; Tierney et al., 2016). There are only a handful of studies, as will be discussed in the Literature Review, that adopt a phenomenological approach to understanding autistic female experiences, offering others insight into their worlds.

1.5 Understanding Autism

To put this research into context, this section will firstly explain how autism is clinically diagnosed, before discussing the current hypotheses aiming to explain why fewer females are diagnosed than males.

1.5.1 Autism Spectrum Disorders

Autism is usually defined as a lifelong neurodevelopmental disorder (Krahn & Fenton, 2012). To receive a clinical diagnosis of Autism Spectrum Disorder (ASD) an individual is assessed by a multi-professional team against the behavioural diagnostic symptomology of the DSM-5 (American Psychiatric Association, 2015) or the ICD-11 (World Health Organisation, 2018). Both manuals typify ASD as having two main areas of deficit: one in social communication and interaction, the second in restrictive and repetitive behaviours and interests, including an element of sensory need.

The DSM and ICD are based upon the current understanding of psychiatry and are under constant review, meaning significant changes can be made between editions (Huynh, 2017). For example, Asperger's was a diagnosis in both the DSM-4 and ICD-10. Yet in the latest editions of both, Asperger's has been removed (Lai & Baron-Cohen, 2015). Therefore, although these descriptions are meant to be standardised and positivist, they can and do change. Notably the diagnostic criteria for autism are behavioural. Information is gathered through observation, activities and interviews with young people and parents to inform diagnosis (Milton & Bracher, 2013). As there

is not yet a known single aetiology or biomarker (Hull, Petrides et al., 2020), behavioural measurements are the only way to diagnose based upon the medical model.

Nonetheless, this medical model definition is deficit-focused and there is an increasing dissatisfaction with the diagnostic process from autistic individuals: some do not agree with having to seek validation from a non-autistic 'autism expert' to be categorised as a series of impairments (Begon & Billington, 2019). Instead there has been a rise in the number of individuals choosing to self-identify as autistic and an increasing number of autism researchers are beginning to describe autism differently (Begon & Billington, 2019; Jaarsma & Welin, 2012).

1.5.2 Misdiagnosis/Missed Diagnosis of Females

There is no disputing that there are fewer females than males clinically diagnosed with autism. However, what is not yet clear is why. Research has found that females are less likely to receive a diagnosis even when presenting with similar levels of autistic-like traits (Dworzynski et al., 2012). They are also more likely than males to be diagnosed at a later age (Begeer et al., 2013; Duvekot et al., 2017; Gould & Ashton-Smith, 2011; Mandy et al., 2012; Rynkiewicz et al., 2019). Additionally, for females, when autistic traits are coupled with low IQ they are more likely to have an autism diagnosis than females with higher IQ (Gould & Ashton-Smith, 2011; Rynkiewicz et al., 2019). Therefore, it is the 'high-functioning' females that are most at risk of remaining undiagnosed (Baldwin & Costley, 2016; Rynkiewicz et al., 2019; Zener, 2019). Nonetheless, an increasing number of females are now being diagnosed (Gould, 2017).

There are a few hypotheses that aim to explain this gender difference. These hypotheses are not mutually exclusive, and it may be any combination that contribute to the challenges and changes in diagnosis for autistic females.

1.5.3 Female Protective Effect

One possible explanation is that there is something inherent in females that needs a higher level of environmental and genetic risk to exhibit autism, compared to males (Hull & Mandy, 2017). There is some supporting evidence from genetic studies (e.g. Volkmar et al., 1993); however, the conclusions from these are undermined by the fact that autistic females included in the research are likely to have a higher expression of autistic traits as they reached diagnostic criteria. Furthermore, although this hypothesis may hold some truth, it does not explain why female diagnosis is increasing.

1.5.4 Female Autism Phenotype

Some researchers think that there is a specific female autism phenotype that previously was unknown, and that the diagnostic process is not sensitive to detecting (Bargiela et al., 2016; Lai et al., 2015; Mandy et al., 2012). For example, diagnosis in females is less associated with restricted and repetitive behaviours than in males (Duvekot et al., 2017). Possibly females express lower levels of these 'typically autistic behaviours', or perhaps female restrictive and repetitive behaviours are qualitatively different to males, for example autistic females are often interested in topics such as literature, psychology or animals instead of the stereotypical interests such as trains (Rynkiewicz et al., 2019).

Furthermore, it has been found that having more emotional and behavioural problems increases the likelihood of a female receiving a diagnosis, although it does not impact male diagnosis (Duvekot et al., 2017). This could mean that autistic females are also more likely to exhibit emotional and behavioural problems than autistic males; or that those without such problems are being overlooked. As there is evidence to suggest that autistic females exhibit fewer externalising and more internalising behaviours compared to males (Hull, Petrides, et al., 2020; Jamison & Schuttler, 2015; Mandy et al., 2012), the latter may be true.

When compared to males, it seems that females need greater impairments spanning a range of the current diagnostic criteria to receive a clinical diagnosis (Duvekot et al., 2017; Hull & Mandy, 2017). As females possibly present behaviourally differently to males, it is the females that exhibit male-typical behaviour that are more likely to be diagnosed; especially as it was majority-male research that contributed to the creation of diagnostic instruments (Hull & Mandy, 2017; Rynkiewicz et al., 2019).

1.5.5 The Camouflaging Hypothesis

A dominant hypothesis within the literature is that females are more likely to camouflage their autistic traits, making autism harder to detect and diagnose. There is a growing body of research investigating this hypothesis, sometimes considered as part of the female autism phenotype (Hull, Petrides, et al., 2020). Camouflaging will be covered in more detail within the Literature Review. Briefly, it encompasses the finding that a lot of autistic females use conscious and unconscious strategies to not stand out from non-autistic peers (Bargiela et al., 2016; Hull, Lai, et al., 2020; Hull et al., 2017). However, by doing this, their difficulties are hidden, meaning that when assessed for autism, their challenges may not be observed to a significant level. Nevertheless, as they mature, these techniques typically become less effective due to the changing social

landscape (Hull et al., 2017; Tierney et al., 2016). Therefore, females are less likely to be diagnosed until their camouflaging becomes ineffective and their difficulties are noticed.

Furthermore, camouflaging has been considered to potentially cause some confusion when diagnosing females, meaning that alternative mental health conditions may be diagnosed instead (Lai & Baron-Cohen, 2015). Thus, camouflaging may contribute to missed, misdiagnosis and later diagnosis of females.

1.6 Aims of This Research

There is a call in the literature for more understanding from the autistic female perspective (Baldwin & Costley, 2016; Kirkovski et al., 2013). It is important to give autistic individuals a platform upon which to communicate their own constructs of autism, and for professionals to understand their emic perspective whilst recognising that multiple versions of autism exist (Begon & Billington, 2019). If professionals are more aware of how females may experience autism, they will be more able to support them in constructive ways. As Cridland and colleagues (2014) recognise, for reasons that will be explored in the following chapter, “adolescence is a critical period for girls with ASD” (p.1262). Therefore, this research aims to understand what adolescent autistic girls’ narratives indicate about how they make sense of, and identify with, their autism. A further aim is to recognise any significant relationships and experiences participants discuss that influenced their identification with their autism. The Methodology chapter discusses reasons for the narrative approach adopted.

1.7 Structure of This Dissertation

This dissertation is organised into chapters to support readers’ navigation and understanding.

Literature Review. This chapter critically explores existing literature to demonstrate what is already known of autistic females’ experiences and identity before highlighting what is not known, and what the current research aims to address. Within this chapter you will also find a discussion of pertinent psychological theories that support analysis. This chapter concludes with the research questions.

Methodology. This chapter describes the methodological approach and design adopted. My epistemological and ontological position will be defined before detailing why Narrative Inquiry was selected. Additionally, the Narrative Oriented Inquiry analysis used is described.

Presentation of Narratives and Interpretation. This chapter presents the narratives of the five young people who participated: Maddison, Olivia, Chloe, Lauren and Emily. Their narratives are individually considered in relation to the research questions.

Discussion. The final chapter of this dissertation includes further discussion of the narratives in relation to the existing literature to draw out meaning and conclusions. Strengths, limitations and implications of this research are also discussed, and a personal reflection of the research process is included. This chapter ends with the key messages that participants wanted others to understand.

2 Literature Review

This chapter presents key literature resulting from a systematic search exploring female autistic identity. Firstly, what is known about females' experiences of being autistic will be presented before discussing relevant psychological theories, including identity theories and labelling theories. The Autistic Community and existing knowledge about female autistic identity will also be covered. Finally, the relevance of this topic to EP practice will be discussed. This chapter offers an understanding of the current knowledge base about autistic females' experiences whilst also recognising areas that are unknown or unclear due to methodological challenges or absence of enquiry. This chapter concludes with the research questions.

This literature review aims to address four questions that were considered necessary to address the research aims:

1. What is known about autistic females' experiences?
2. What psychological theories can inform us about adolescent autistic girls' understanding of their autism?
3. What influences females' reactions to receiving an autism diagnosis?
4. What is the relevance of the topic for EPs?

2.1 Search Strategy

In order to address the questions above, a systematic search strategy was used to effectively access a wide range of literature using explicit and transparent methods (J. Collins & Fauser, 2005). Systematic searches using database search engines Ovid (accessing PsycInfo) and Web of Science identified initial key literature. PsycInfo was chosen to access psychological research and Web of Science to access a broader range of publications. It was considered that these databases provided a good range of papers (many of which were duplicates) so no further databases were searched. Following this, further searches were conducted in Google Scholar using key terminology. Forward citation and 'snowballing' (Wohlin, 2014) contributed further papers. The key search terms included diagnostic labels of autism, terms relating to 'female', and identity. The specific terms and number of results can be found in Appendix A. Reasons papers were excluded includes not having autistic females in their sample, the use of methods that did not elicit the perspectives of autistic females and critical accounts of therapeutic input, among others. The systematic searches conducted on 13.12.19, and repeated on 02.04.20, resulted in 28 papers; additional literature searching provided a supplementary 19 papers. Date and

geographical limits were not set due to the limited literature about autistic females' identities, although all papers were English and included autistic females in their sample. The studies included were conducted in Australia, Canada, USA and the UK, meaning there is an inherent Westernised perspective; nevertheless, this is also the culture within which the current dissertation is situated. Furthermore, all of the countries endorse diagnosing autism using the DSM-5 either by a multi-professional team or medical professional. Moreover, though potentially related for some individuals, papers exploring gender identity specifically were not included. It is important to recognise the high rate of gender dysphoria within the autistic population which exceeds that of the general population (Glidden et al., 2016). Nevertheless, the decision to not include these papers was made as gender identity is a unique aspect of an individual's identity (Kaltiala-Heino et al., 2018) therefore research in this area is not aiming to investigate participants' understanding of autism which is the focus of the current research.

2.1.3 Important Considerations

Interestingly, seven papers reviewed were Masters or Doctoral dissertations. As it can be assumed that a dissertation has undergone external review by content experts, they can be useful especially in areas where there is little else (Hartling et al., 2017), such as within the field of autistic female identity. The closest research to the current topic were phenomenological dissertations thus they significantly contribute to this literature review. If a piece of research was a dissertation, this will be indicated when discussing the findings.

Many studies used samples of individuals with Asperger's diagnoses, yet Asperger's is no longer an official clinical diagnosis. This is significant as Asperger's can be understood as a distinct identity to 'autistic', which led to much discord when the diagnosis was removed (Huynh, 2017). Being diagnosed with Asperger's can potentially impact differently due to the specific, and often more positive connotations of Asperger's as opposed to autism (Huynh, 2017). For transparency, I will use the term 'Asperger's' where this is true of the research. The Asperger's research has been reviewed as it describes individuals' autism experience and offers conceptual and inferential generalisability, aligning with the epistemological stance of qualitative research (B. Smith, 2018).

Notably, similar to the male literature, the majority of reviewed research recruited autistic females described as 'high-functioning' (inclusive of Asperger's) i.e. those who can express a viewpoint (Begon & Billington, 2019). This is often because the methods used inherently require communication with a researcher, usually through interview. Therefore, the experiences and conclusions described may only be hypothetically reflective of autistic females with similar

language and communication abilities; thus, this is often cited as a limitation of the literature. However, there are some researchers that discuss this is only a limitation if assuming that because 'low-functioning' autistic individuals are not able to express themselves in words, that they are also void of a subjective worldview (Begon & Billington, 2019). Therefore although predictive generalisability may not be 'accurate', predictive generalisability is not the aim of phenomenological research (B. Smith, 2018). Consequently, the strength is instead the depth of exploration and the recognition of the heterogeneous experiences of autistic females, as every participant is unique even when sharing a diagnostic label. This research and literature review therefore is not aiming to homogenise the perspectives of autistic females, something that is endemic in autism research (Begon & Billington, 2019), but instead gather the experiences of autistic females, recognising commonalities, but not making assumptions for all from these.

Where possible, the literature chosen focuses upon adolescence as it has been identified as a critical period for autistic females (Cridland et al., 2014) and a key time for identity formation (Erikson, 1968). It is recognised that adolescence is a developmental stage with wide variation, not only of ages (12-19 years) but also experiences. Moreover, different cultures define adolescence differently (P. Smith, 2016). This is additional to considerations about the adolescent brain and how neural mechanisms and thus brain functioning changes during adolescence typically making individuals more impulsive and engaging in risk-taking behaviours (Casey, 2008). This is important to acknowledge when considering identity development as an individual may frequently appear to change their behaviour and identity roles during adolescence. Nevertheless the identity theories discussed in Section 2.3 allow for this variation as an individual fluctuates through different identity statuses.

2.2 Autistic Females' Experiences

This section will present what is reported about female experiences of autism in the areas of: friendships, familial support, school experiences, challenges, and the positives. Understanding the range of possible experiences is important to understand identity, as an individual's perception of their autism will not only be influenced by their construct of the diagnosis, but also their experiences related to their autistic traits (Mogensen & Mason, 2015; Punshon et al., 2009). Capturing the perspectives of autistic females is imperative for this understanding.

2.2.1 Friendships

Qualitative differences have been found between male and female friendships. Compared to boys, girls are encouraged to be more nurturing and passive and tend to have smaller and more

intimate friendship groups (Blatchford et al., 2003; Freeman & Kasari, 1998). How adolescent girls and boys show aggression to one another also differs as adolescent girls are more likely to use subtler and more socially complex techniques such as gossiping and rumours (Card et al., 2008) requiring more relational interpretive skills (Dean et al., 2013). Many autistic females have reported finding navigating adolescent relationships difficult (Cook et al., 2018; Cridland et al., 2014; Myles et al., 2019; Sedgewick et al., 2019; Tierney et al., 2016; Vine Foggo & Webster, 2017) and may not intuitively learn the implicit social rules that govern the teenage social world (Edwards, 2012; Logsden, 2010; Moyse & Porter, 2015). This is significant because during adolescence peers become more influential (McElhaney et al., 2008; P. Smith, 2016) and can affect emotional wellbeing and identity formation (W. Collins & Laursen, 2004).

Sedgewick and colleague's (2019) mixed-methods research in the UK investigated the friendship and conflict experiences of 102 adolescents through self-report questionnaires and interviews. Their analysis, which was split by diagnosis (autistic or non-autistic) and gender (female or male), indicated that gender was more significant to differences in friendships than diagnosis, at least within mainstream populations: autistic female friendships were more similar to non-autistic females than autistic males. Importantly, although it has been previously asserted that autistic individuals do not want friendships due to their isolating social behaviour (Kanner, 1943), emerging research is contradicting this (Sedgewick et al., 2016). Cook et al. (2018) spoke to 11 adolescent autistic girls and their parents in the UK. One theme that emerged was the *motivation to have friends* which was noted to contrast themes from the replicated study with autistic boys (Cook et al., 2016). The desire of autistic females to have friends has been repeatedly reported in the literature from autistic females themselves, internationally and across ages, adding to this conclusion's credibility (Beteta, 2009; Gaffney, 2017; Kock et al., 2019; Milner et al., 2019; Myles et al., 2019; Rainsberry, 2016; Tierney et al., 2016; Vine Foggo & Webster, 2017). Yet, autistic females may show a preference for smaller groups than a non-autistic female, and stay on the 'periphery' of larger groups (Myles et al., 2019). In Vine Foggo and Webster's (2017) phenomenological research seven Australian autistic girls unanimously described social interaction and the resulting mental health benefits as important. Nonetheless, three reported also needing time alone. Previously the time alone was thought to represent a lack of social motivation (Kanner, 1943); instead participants described this was to de-stress and self-regulate. This highlights the importance of understanding their emic perspective as initial assumptions can be incorrect (Brownlow, 2010). Eight autistic girls spoke about recognising the value of friendships for inducing a sense of belonging, which they associated with happiness (Myles et al., 2019).

Conversely, Baldwin and Costley's (2016) questionnaire revealed 27% of 82 Australian autistic women *preferred* to be alone than with others. Yet the idea of not wanting social interaction is not everyone's experience. However it is also important to note that Baldwin and Costley's respondents were adults (18+ years), and Vine Foggo's and Webster's were adolescents (13-17 years), therefore developmental differences in motivation for social interaction (McElhaney et al., 2008; P. Smith, 2016) may influence this variance.

Irrespective of motivation, social interaction challenges for autistic girls are described by autistic females themselves and their parents, such as: difficulties in understanding friendship expectations and social rules; autodidacticism (being a self-taught person); feeling different to 'typical teenagers'; managing conflict; limited social and communication skills; and social isolation (Beteta, 2009; Cook et al., 2018; Cridland et al., 2014; Feist, 2013; Goodall & MacKenzie, 2019; Haney & Cullen, 2017; Kanfiszer et al., 2017; Logsden, 2010; Milner et al., 2019; Moyse & Porter, 2015; Rainsberry, 2016; Sedgewick et al., 2019; Tierney et al., 2016; Vine Foggo & Webster, 2017). 'Camouflaging' and bullying also commonly emerge as themes when considering friendships; these will be covered later in this section.

2.2.2 Familial Support

Although not generally a coded theme, a noticeable contribution to autistic females' lives can be their familial support. Often mothers, and occasionally fathers, are referred to when females discuss managing their autism. This seems to be implicitly understood by some researchers who included parents in their samples alongside autistic girls (Cook et al., 2018; Cridland et al., 2014; Jarman & Rayner, 2015; Milner et al., 2019; Rainsberry, 2016). For example, Cridland et al. (2014) spoke to five Australian mothers who described having to 'fight' for their concerns to be taken seriously. These mothers also described challenges such as difficulties for their daughters accessing the school environment and social interaction, as well as heightened vulnerability. Furthermore, based in the US, Beteta's (2009) four dissertation participants shared how their mothers influenced their lives. One participant described her mother protecting her by avoiding anxiety-provoking situations. Another mother described actively teaching her daughter independence skills such as cooking and cleaning; whilst another helped her daughter's school access training. Tierney et al. (2016) similarly reported one UK mother trained staff members to not take her daughter's outward smiley appearance for granted, as underneath she was struggling. It seems clear from the literature that parents can be highly influential upon their daughters' lives through the support they offer in managing specific difficulties, and this is true across Western geographical locations.

Contrastingly, one participant in Logsden's (2010) dissertation mentioned her mother's denial of her diagnosis. This participant also discussed her low self-esteem and related this to her father and stepmother's non-acceptance of some of her behaviours; highlighting how the acceptance of parental figures can impact upon individuals' sense-of-self. Interestingly, Milner and colleagues (2019) discussed one UK mother's personal feelings towards having an autistic child. The quotation revealed the mother's grief about her child missing out on the life 'anticipated' for them. However, the researchers only included one quote and did not reflect if other parents had contradictory or similar feelings. This highlights the complexity of diagnosis for parents too (Smith-Demers, 2018). Parental reactions can change their daughter's perception. Yet it is important to recognise that the way that autism is both understood and experienced is culturally dependent, therefore even within Westernised societies there can be multiple discourses around autism (Begon & Billington, 2019). Thus, to truly understand the reactions and influence of family, it is also important to acknowledge the intersectionality of the individual's culture and beliefs about disability (Theara & Abbott, 2015).

2.2.3 School Experiences

Much of the literature explores autistic girls' school experiences, often qualitatively capturing their perspective (Baldwin & Costley, 2016; Cook et al., 2018; Cridland et al., 2014; Edwards, 2012; Goodall & MacKenzie, 2019; Moyse & Porter, 2015; Rainsberry, 2016). A review by Gould and Ashton-Smith (2011) discusses educational implications for autistic girls including: differences in cognitive styles and skills to autistic boys; lack of staff awareness of the 'hidden curriculum' (social norms that are usually learnt implicitly, but autistic individuals may need explicit teaching) and the need to focus upon girls' wellbeing, self-confidence and mental health. Published in 2011, the aim was to raise awareness for autistic girls, and it has been cited many times since. However, the authors do not indicate how they collated the information. Nevertheless, many of the implications raised have subsequently been empirically investigated: Tomlinson et al. (2019) conducted a systematic review of eight papers to understand autistic girls' school experiences and concluded that although similarities to autistic males exist, there are some distinct female experiences; confirming those Gould and Ashton-Smith (2011) discussed.

2.2.3.1 Accessing the Curriculum. Autistic children are at a higher risk of underachieving academically than non-autistic peers (Howlin, 2005). However this is often not due to academic ability, but instead autism-specific challenges such as executive functioning difficulties and inflexible thinking (Kirkovski et al., 2013). Some research suggests autistic females have more severe executive functioning deficits compared to autistic males and non-autistic children (Lemon

et al., 2011). However not all research has replicated this finding quantitatively (Nydén et al., 2000). Nevertheless, the samples used were not directly comparable as Nydén and colleagues were researching neuropsychiatric conditions more generally. Anecdotally, 53% of 82 autistic women self-reported problems with attention and concentration (Baldwin & Costley, 2016). The accompanying comments revealed that often these needs were overlooked and unsupported by teaching staff leading to underachievement, a conclusion Tomlinson et al. (2019) also drew. However, Baldwin and Costley's (2016) research was conducted in Australia and captured adults reflecting upon the education system when they attended school. Therefore, the educational experiences of their participants will differ to current UK students, potentially limiting the applicability.

Nevertheless, Moyse and Porter (2015) found similar results in the UK. They considered the influence of the 'hidden curriculum' upon three autistic girls, finding that misunderstanding implicit social norms also contributed to difficulties accessing learning. From their interview and observation data they concluded that autistic girls are less likely to intuitively learn these rules, and are more likely to internalise their difficulties, thereby increasing chances of being overlooked. This is also supported by Myles et al.'s (2019) participant Sophia who explained that she explicitly educated herself on the hidden social rules upon entering secondary school.

2.2.3.2 Teaching Staff. An important factor of any child's school experience is the staff (Rainsberry, 2016; Tomlinson et al., 2019). Moyse and Porter (2015) interviewed autistic girls, their parents, class teachers and SENCos. Even though their sample size was small, three participants, it was an illuminating piece of research comparing multiple views of the girls' experiences, offering a rich analysis. Their analysis revealed that school staff were not aware of the impact of the hidden curriculum upon the girls. As a result, staff were not always supporting girls effectively, such as explicitly communicating expectations, having consistent class rules and checking their comprehension. Notably these strategies also have generic applicability to other children, yet beyond what is typical, they are further applicable to autistic students (McCann, 2018). Moreover, some school staff misunderstood how well the girls were managing and enjoying school. One participant's teacher thought she enjoyed school 'very much'; whereas she rated it only 'slightly higher than okay'. The girls' coping mechanisms, like masking and internalising their difficulties, meant teachers did not recognise the full impact of their diagnosis, as on the surface they were managing. This has significant implications upon girls receiving support, particularly as the lack of observable difficulty even led some teachers to question their diagnoses.

Similarly Milner and collegaues (2019) worked with 18 autistic females (11-55 years) and four mothers of autistic daughters in the UK. The wide age range of participants enabled them to capture varied experiences. Some of their participants referred to a lack of school support and being labelled as a 'naughty child' or a 'slow learner' instead of teachers understanding their individual strengths and needs. Nevertheless, these comments may also reflect the culture at the time of their schooling as they were shared by older participants (30+ years). Significantly, two self-diagnosed autistic females were included in the sample so as not to exclude females who may be missed due to challenges in diagnosing females. The authors considered this as the right direction for autistic research, but also that it should be done carefully. Following this precedent would impact upon sampling techniques and risks reinforcing a diagnosis by inclusion in autistic research, having ethical implications. Nevertheless, to strengthen their validity, Milner et al. checked for differences between the responses of those clinically diagnosed and self-diagnosed and found none, so included all responses in analysis. Including self-diagnosed individuals in autism research is something that is likely to become more common with the increase of awareness of self-diagnosis, particularly for females. However perhaps more robust measures should also be introduced for inclusion such as using the Autistic Quotient (AQ) self-report measure (Baron-Cohen et al., 2001) or the shorter version AQ-10 (Allison et al., 2012) which is already widely used. Typically the AQ-10 is considered to indicate autism if scoring 6+ positive answers which was corroborated with roughly equal number of male and female participants (Allison et al., 2012) thus may not be subject to the male-bias of other measures. Yet it is important to note that then the females included in the sample reach diagnostic levels, thus still may misrepresent all autistic females. Careful and considerate application of these types of measures is necessary.

Similar themes to Moyse and Porter's (2015) and Milner et al.'s (2019) research have been found by Jarman and Rayner (2015) using a larger sample of autistic women (n=30; 18+ years) and mothers of autistic girls (n=15). They used an online survey to investigate what participants wished teachers knew. Notably they were investigating Asperger's specifically and in Australia, however the similar experiences described by Jarman and Rayner's participants when compared to Moyse and Porter's (2015) and the inductive methodologies demonstrates that these are common experiences across the diagnostic labels and Western cultures. Jarman and Rayner's research revealed themes such as *teachers' recognition of the Asperger's diagnosis in females* within which teacher's disbelief of diagnoses was discussed. Secondly, the *lack of understanding about the challenges associated with Asperger's* was a theme encompassing poor flexibility with

teaching approaches. Yet it is also important to consider the cohort of participants and the context of autism at the time of their schooling as two thirds of their sample were autistic adults. However, one third of their participants were mothers of current students and also contributed to these themes. Sensory factors of the environment were also mentioned as a major challenge (explored further in Section 2.2.3.3). Participants also discussed difficulties with understanding instructions, organisation, planning, time management, and prioritising; reinforcing Kirkovski et al.'s (2013) review's finding of executive functioning difficulties. Jarman and Rayner's participants also highlighted a reluctance to ask for help so as not to inconvenience teachers, or cause teachers to be angry or upset. Although it would have also been interesting to understand teachers' perspectives, whilst not discrediting the viewpoint of their participants, this was not within the scope of Jarman and Rayner's procedure. Nevertheless, relationships with teaching staff are highly influential upon an autistic females' experience of school. Furthermore, it is striking that in Baldwin and Costley's (2016) online survey, 46% of participants stated 'lack of support' as one of the three worst things about their education. Synthesising these results illustrates that autistic girls can go unnoticed and unsupported in school; some are not happy to ask for help for fear of upsetting the teacher and so increase their compensatory activities, such as masking, to appear 'normal', leading to further unrecognition.

Importantly, Jarman and Rayner's (2015) research was not only negative, and participants also described *helpful attitudes and actions of teachers*. Similarly, Rainsberry's (2016) dissertation research captured some helpful adjustments described by autistic girls such as having a tray in the classroom instead of a locker in the corridor, attending extracurricular clubs, and eating lunch in a quieter space. When Baldwin and Costley (2016) asked autistic women for the three best things about their education, 32% of participants cited the support they *had* received. The women and parents in Jarman and Rayner's research described that their best experiences were when teachers took a personal approach because they understood the girl's needs, made adaptations, communicated with parents, and made the girls feel valued and liked. This led to recommendations of dispelling autistic stereotypes through improved awareness. They also recommended that adjustments should be made even if girls are coping academically, an endorsement reinforced by Moyse and Porter (2015) and Tomlinson et al. (2019).

2.2.3.3 The School Environment. Autistic girls can also face challenges at school when navigating the physical school environment (Tomlinson et al., 2019). Much research has investigated the sensory experiences of autistic individuals, commonly finding both hyper- and hypo-sensitivities (e.g., Saggers et al., 2020; Sciutto et al., 2012). Although this is largely based

upon male samples, females also indicate sensory sensitivities, which can directly impact them in school (Davidson, 2007).

Autistic female participants have reported their sensory sensitivities impact them every day, mainly negatively (Milner et al., 2019; Tierney et al., 2016). School-based triggers include noisy lunch halls and corridors, the general proximity of people (Rainsberry, 2016); disliking the uniform material and a hypersensitivity to noise directly impacting concentration, and consequently school performance (Feist, 2013); fluorescent lights causing headaches, hypersensitivity to noise and disruption, and difficulty holding pens (Jarman & Rayner, 2015). These could all have a secondary impact on executive functioning and academic performance, leading to the difficulties already discussed. Nevertheless, from speaking with eight adolescent autistic girls, Myles et al. (2019) reported how a sense of belonging, often instilled by friendships or support within school, can be a protective factor when managing an uncomfortable environment. Furthermore, sensory sensitivities are not always negative experiences. One woman reported a positive, euphoric feeling associated with music (Milner et al., 2019). Another girl described her synaesthesia (when one sense is processed as another, e.g. hearing colours), which is more common in autistic individuals than the general population (Baron-Cohen et al., 2013), positively and as enhancing her musical ability (Feist, 2013).

Although the research discussed in relation to autistic female sensory issues is relatively small-scale, it begins to indicate the diverse sensory experiences which can be both positive and negative. Thus, illustrating some of the hidden difficulties autistic girls may experience in school.

2.2.4 Challenges

Additionally to the experiences described above, there are specific challenges that also warrant discussion such as camouflaging, social vulnerability and mental health.

2.2.4.1 Camouflaging. It is increasingly recognised that some autistic females use compensatory strategies to hide their autism, which is hypothesised to contribute to the under-identification of females, as aforementioned (Gould & Ashton-Smith, 2011; Hull & Mandy, 2017; Hull et al., 2017; Kirkovski et al., 2013; Milner et al., 2019). ‘Camouflaging’ has received increasing research attention in recent years aiming to understand why, how, and its impact. Camouflaging is defined as: “[hiding] behaviours associated with their [autism], using explicit techniques to appear socially competent, and finding ways to prevent others from seeing their social difficulties” (Hull et al., 2017, p.2519). As a concept, camouflaging has been operationalised, and a

statistically corroborated self-report measure of camouflaging created by Hull and colleagues (2019). They describe camouflaging as having three distinct factors:

1. *Compensation:* behaviours individuals use to compensate for their social difficulties. Including copying body language or facial expressions, or explicitly researching social interaction rules.

2. *Masking:* behaviours to hide any autistic traits and presenting a 'less-autistic persona'. Including monitoring their own facial expressions to appear relaxed and being aware of their impression on others.

3. *Assimilation:* behaviours used to fit in without others detecting discomfort. Including putting on an act or creating a new persona; 'performing' rather than being themselves.

Some believe there is more pressure for autistic females as opposed to males to camouflage due to gendered expectations and female tendency to be more self-aware (Dean et al., 2017; Hull et al., 2020; Milner et al., 2019; Tierney et al., 2016). Nevertheless, it must be recognised that camouflaging to some extent is also seen in the general population (Hull et al., 2017) in addition to autistic males and non-binary autistic individuals, and not all autistic females camouflage (Hull et al., 2020; Milner et al., 2019). Yet, research does suggest that camouflaging is more common (Hull et al., 2020; Lai et al., 2017) and can be more extreme and detrimental to autistic females than autistic males, somewhat because they are so successful at it (Bargiela et al., 2016; Hull et al., 2017; Milner et al., 2019; Tierney et al., 2016).

Notably, the female social world may be more conducive to camouflaging than the male social world. Dean and colleagues (2017) used data from a previous project (Kasari et al., 2016) that observed children (average age 7-years-old) during 'recess' in the US to code social behaviours split by sex and diagnosis. Results indicated autistic girls used compensatory behaviours to mask their social communication needs such as staying in close proximity to other girls, thus appearing the same as non-autistic girls. Yet upon closer observation, the girls were not socially engaging. By contrast, the autistic boys engaged less in the typical group games of non-autistic boys and instead wandered alone; meaning they were more conspicuous and consequently received more support. This is also echoed in Myles and colleagues' (2019) research; their findings from interviewing eight autistic girls indicated that autistic girls can appear part of a social group but without being fully integrated, so remain on the periphery. Therefore, although camouflaging has been identified as a conscious and purposeful technique, self-report interview and naturalistic

observation of autistic females indicates that the social landscape of females is more conducive to it, as typical socialising behaviour does not overtly isolate a girl that is not fully engaging.

Both adult and adolescent autistic females have reported consciously camouflaging, aiming to not appear different and to make friends (Bargiela et al., 2016; Cook et al., 2018; Cridland et al., 2014; Hull et al., 2020, 2019, 2017; Leedham et al., 2020; Logsden, 2010). They may explicitly develop strategies, scripts or personas for social situations through researching or observing others (Bargiela et al., 2016; Cook et al., 2018; Cridland et al., 2014; Hull et al., 2019; Logsden, 2010; Milner et al., 2019; Tierney et al., 2016). However, camouflaging is not always conscious; autistic females may also automatically mimic others, such as copying body language and accents (Bargiela et al., 2016; Hull et al., 2017). Camouflaging can be incredibly successful for blending in and making friends, however the potential negative consequences of this are now becoming clearer.

Firstly, females can remain unnoticed and therefore unsupported as they outwardly appear to be managing (Gould & Ashton-Smith, 2011; Hull & Mandy, 2017; Hull et al., 2019, 2017; Logsden, 2010; Milner et al., 2019; Tierney et al., 2016). Secondly, camouflaging results in extreme exhaustion from intense self-regulation during social interactions (Bargiela et al., 2016; Cook et al., 2018; Hull et al., 2017; Logsden, 2010; Milner et al., 2019; Tierney et al., 2016). As camouflaging has also been positively correlated with internalisation of problems, this then increases stress and anxiety and negatively impacts psychological wellbeing (Allely, 2019; Cook et al., 2018; Hull et al., 2020; Livingston et al., 2019; Tierney et al., 2016).

A less reported consequence of camouflaging is its impact upon identity (Cage & Troxell-Whitman, 2019; Leedham et al., 2020; Zener, 2019). Some women describe that engaging in camouflaging causes them to lose a sense of who they are (Hull et al., 2017) leading to confusion about their true identity (Bargiela et al., 2016). It can impact upon their sense-of-self through feeling that their true self is intrinsically flawed and needs to be hidden (Leedham et al., 2020; Zener, 2019). Interestingly, these samples were adults which may have changed their perspective regarding their identity compared to adolescents due to differing developmental stages. Yet, camouflaging was also described by one adolescent participant to have led to an identity crisis (Tierney et al., 2016). Importantly, Hull et al. (2017) also identified two ways autistic adults conceptualise camouflaging: (1) as a performance, and (2) as lying. Some participants that perceived camouflaging as lying then believed their relationships were based upon deception. One participant described ending her marriage after 15 years because she had camouflaged for

its entirety and had lost a sense of the ‘real her’. It is suggested, but not yet explored, whether the different conceptualisations mediate the consequences.

Therefore, although camouflaging can be a successful short-term technique, in the long-term it not only reduces the chance of accessing support but can also negatively impact psychological wellbeing and identity.

2.2.4.2 Social Vulnerability. There is often a significant level of social vulnerability associated with autism due to the characteristic social and communication difficulties (Bargiela et al., 2016; Cridland et al., 2014). As a population, autistic individuals are particularly susceptible to bullying (Cappadocia et al., 2012; Cook et al., 2018; Haney & Cullen, 2017), with Sterzing and colleagues (2012) stating a fourfold increase in likelihood of being bullied compared to non-autistic peers. Autistic females are more likely to experience relational bullying such as being ignored rather than overt bullying, which can be less obvious to adults (Myles et al., 2019) but also possibly the girls themselves. Bullying emerged as a theme from many different papers with autistic females, demonstrating the commonality of the experience and the detrimental impact on mental health, self-esteem and self-concept (Bargiela et al., 2016; Beteta, 2009; Cook et al., 2018; Cresswell & Cage, 2019; Cridland et al., 2014; Goodall & MacKenzie, 2019; Haney & Cullen, 2017; Zener, 2019). Moreover, Greenlee et al. (2020) found negative effects of bullying, or peer victimisation, were further exacerbated in autistic females compared to autistic males, as females are more likely to internalise the victimisation impacting upon their mental health and self-concept. This information was gathered with self-report measures from 105 autistic girls (n=50) and boys (n=55) and was triangulated against parent and carers’ reports also. Nevertheless, as the authors recognise, the measures they used to capture the adolescents’ experiences were validated with non-autistic cohorts. This is important as there is some evidence that the examples of peer victimisation provided by autistic individuals are different to those typically assessed on bullying questionnaires (Fisher & Taylor, 2016).

Another vulnerability that has emerged and has warranted specific investigation is sexual exploitation (Rynkiewicz et al., 2019) which is a concern that typically begins to arise in adolescence (Cridland et al., 2014). Half of Kock and colleagues' (2019) eight autistic female participants from the UK recounted being taken advantage of sexually. Similarly, 9 of 14 participants of the same demographic reported sexual abuse in Bargiela et al.'s (2016) study. This is an alarmingly high proportion in both. However, these were both small scale studies with self-selecting participants, which may skew the proportions. Importantly, Bargiela et al.'s (2016)

participants were all diagnosed as adults, and 57% suggested their life would have been easier with an earlier diagnosis. Participants described if they had been more aware of their vulnerabilities, they could have actively addressed them. Moreover, a larger study by Brown and colleagues (2017) with 34,879 undergraduate students found that overall, autistic and disabled students have greater risk of experiencing unwanted sexual contact than other students. Additionally, autistic women and non-binary individuals have a significantly increased risk compared to autistic males, highlighting the specific vulnerability of this population.

These vulnerabilities can lead parents to feel they need to protect their daughters (Cridland et al., 2014), although, there is a sensitive balance between independence and vulnerability (Gould & Ashton-Smith, 2011). Autistic adults have reported feeling over protected and consequently being denied independence during childhood (Gould & Ashton-Smith, 2011). Unintentionally protecting may instead increase dependency and subsequently, vulnerability. Therefore, even though population-level intervention to reduce abuse of vulnerable women would be ideal, as Bargiela et al. (2016) suggests, specific training programmes should be developed to enable autistic females to keep themselves safe.

2.2.4.3 Mental Health. It is commonly acknowledged that autistic individuals are at increased risk of developing mental health conditions (Cage et al., 2018; Lai et al., 2015; Rynkiewicz et al., 2019; Tantam, 2000) particularly during adolescence (Vickerstaff et al., 2007). It is suggested that this risk is further exacerbated for autistic females (Baldwin & Costley, 2016; Lai & Baron-Cohen, 2015; Rynkiewicz et al., 2019; Zener, 2019). Baldwin and Costley's (2016) online questionnaire found 85% of autistic women self-reported having a mental health condition, which statistically differed to 67% of autistic males. Although, not all research identifies a gender difference (Cassidy et al., 2014; Kirkovski et al., 2013) and different measures may lead to reporting biases.

Nonetheless, it is very common for females to be diagnosed with mental health conditions before autism (Feist, 2013; Hull et al., 2017; Lai & Baron-Cohen, 2015; Milner et al., 2019; Tierney et al., 2016). For example, Milner et al. (2019) found that 16 of 18 autistic women reported having diagnosed comorbid conditions including anxiety, obsessive compulsive disorder and depression. Some argue that these conditions may be misdiagnosed autism (Begeer et al., 2013; Feist, 2013; Gould & Ashton-Smith, 2011; Hull et al., 2017; Milner et al., 2019). But it is also recognised that having undiagnosed autism and managing the associated challenges increases the likelihood of developing secondary mental health conditions (Beteta, 2009; Cook et al., 2018; Cridland et al.,

2014; Feist, 2013; Gould & Ashton-Smith, 2011; Tierney et al., 2016). Thus, there is a recognised connection between autism and mental health conditions affecting many autistic females.

2.2.5 Positives

Despite the challenges experienced that are usually the focus of research, there are positives associated with autism that are often unreported (Milner et al., 2019). These include experiences of euphoria when enjoying a sensory sensitivity (Milner et al., 2019) and positive emotions when discussing a special interest (Beteta, 2009). Edwards' (2012) dissertation participant, 'Katie', described having a very positive high school experience in the US because she loved learning about anything, which she attributed to her Asperger's. This trait was also eluded to in Tierney et al.'s (2016) research in which autistic women discussed being able to 'naturally absorb' information. Other research highlights talents that participants attribute to their autism including: having a different and unique perspective (Milner et al., 2019); strong observation skills (Tierney et al., 2016); a long attention span (Milner et al., 2019; A. Webster & Garvis, 2017); good memory (Milner et al., 2019; Tierney et al., 2016); improved empathy (Milner et al., 2019; Tierney et al., 2016); creativity (Feist, 2013; Gaffney, 2017; Milner et al., 2019); strong sense of justice (Milner et al., 2019) and specifically for Asperger's, good expressive language (Beteta, 2009) and advanced intelligence (Feist, 2013). Although these strengths and talents and whether they are attributed to autism is individualistic, it is an encouraging progression in the literature to acknowledge positives. Milner et al. (2019) found that only one participant out of 18 was unable to identify positives associated with her autism.

2.3 Psychological Theory

There are many psychological theories that could be relevant to the current research. Below I will discuss those that were considered most useful. Others were considered and discounted, for example Acculturation Theory, which was originally developed for ethnic minorities (Sam & Berry, 2010) and has been applied to identification with the Deaf Community. Based upon theoretical generalisation, Acculturation Theory has also been applied to the Autism Community (Cresswell & Cage, 2019; Jarrett, 2013). Nevertheless, it was not found as transferable or useful in these studies; therefore, it has not been used here. Instead, I will first cover three theories of identity selected for their significant contributions to the understanding of identity. Although later versions also exist (e.g. Luyckx et al., 2005), these were not considered helpful in the context of this research. Theories of labelling will also be discussed. These psychological frameworks will be reflected upon to consider how they can be helpful for understanding adolescent females' autistic identities.

2.3.1 Identity

Identity is a concept that has many definitions. For this research, the definition used is provided by Fearon (1999) who described identity as consisting of two dimensions: a *personal identity,* characteristics an individual assigns to themselves that they take pride in or perceive as unchangeable; and a *social identity,* the concept that a person assigns themselves to social categories which characterises their beliefs and behaviours. The idea that identity can be understood in these two dimensions is widely acknowledged within the literature (Stets & Burke, 2000). Importantly, due to their socially constructed foundations, both personal and social identities are dynamic and can change throughout an individual's life based upon assimilated experiences (Bagatell, 2007; Baines, 2012). Below I will discuss two complementary theories of personal identity before Social Identity Theory.

2.3.1.1 Psychosocial Stages Theory. Erikson's (1968) model represents psychosocial development across the life span, including identity formation. Erikson posited that personality development results from addressing psychosocial crises at progressive developmental stages. Erikson pioneered the idea of a connection between identity development and mental health (Cresswell & Cage, 2019). There is an increasing body of research that supports the notion that a synthesised sense-of-self is positive for wellbeing and protective against internalising and externalising problems (Crocetti et al., 2013; Jamison & Schuttler, 2015; J. Ritchie et al., 2013). Erikson's model includes eight progressive stages; the stage that is pivotal for identity formation is the fifth that occurs during adolescence (12-19 years). During the *identity vs. confusion* stage, a favourable resolution leads the individual to develop a sense-of-self and personal identity. However, if unresolved, the individual will experience 'role confusion' and a lack of identity clarity. Therefore, adolescence is a key time for identity formation. Marcia expanded Erikson's fifth stage to consider how individuals resolve the identity vs. confusion crisis.

2.3.1.2 Marcia's Four Identity Statuses. Following empirical investigations, Marcia (1966) created four statuses to describe identity variation within the identity vs. confusion stage based upon differing levels of *role exploration* and *commitment*:

1. *Identity diffused* is low in both exploration and commitment; individuals in this state have not begun to explore alternative identities.
2. *Identity foreclosure* is characterised by low exploration but high commitment, these individuals are mostly driven by identities ascribed by others; this status has been correlated with the lowest self-esteem scores.

3. *Identity moratorium* is high in exploration and low in commitment; these individuals explore numerous roles but have yet to commit.
4. *Identity achieved* is characterised by high exploration and commitment; this is seen as the ideal state of identity and has been correlated with the most secure self-esteem scores.

Adolescents will fluctuate between these statuses until they reach 'identity achieved', resolving their identity crisis; yet this process may continue into adulthood for some (Kroger et al., 2010). In the context of this research, Marcia's theory offers a framework to understand whether participants explore and commit to an identity related to their autism diagnosis.

2.3.1.3 Social Identity Theory. Social Identity Theory (Tajfel & Turner, 1979) explains how an individual's social identity can be influenced by their in-group and out-group affiliations (Macleod et al., 2013). There are three mental processes to developing a social identity.

The first is *social categorisation* in which an individual sorts people into an in-group based upon similarities with themselves and an out-group, without that similarity (Hogg & Reid, 2006; Stets & Burke, 2000). This allows others to know some information about individuals based upon group association (Hogg & Reid, 2006). Although this can be helpful, it can also lead to stereotyping and judgements especially due to the tendency to over-exaggerate differences between groups and similarities within groups (Tajfel & Turner, 1979).

The second mental process is *social identification* in which an individual adopts the identity of the assigned group. From here, the individual's self-esteem relies upon the evaluation of their group membership (Hornsey & Hogg, 2000). The extent to which an individual adopts the group identity and conforms to the norms can also lead to depersonalisation (Stets & Burke, 2000) whereby the individual's personal identity is superseded by the group's.

The final stage is *social comparison,* which was originally developed as a separate theory by Festinger (1954). Individuals compare their assigned group with others in both downward and upward comparisons. It is known that groups will find negative attributes of out-groups in order to raise their own self-image and self-esteem by downward comparison (Hogg, 2000; Stets & Burke, 2000). Therefore it is through social comparison that the 'them' and 'us' mentality is created leading to discrimination and stigmatisation (Tajfel & Turner, 1979).

For this research, Social Identity Theory will be used to consider if and how individuals construct an autism social identity. It is also helpful to consider how imposed stereotypes may influence their association with their autism.

2.3.2 Consequences of Labelling

Scheff (1966) developed Labelling Theory to capture the negative effects of mental illness labels. Although Labelling Theory specifically considers 'mental illness' and many would dispute if autism is an illness or disorder, historically it has been portrayed as one in society (Kapp et al., 2013). Scheff (1966) discussed that labelling causes someone to become mentally ill as stereotypes of, and stigma associated with, mental illnesses are learnt during childhood. Once labelled, the individual begins to present themselves in the 'expected' way, leading to a self-fulfilling prophecy. Thus, mental illness is a social construction.

Yet, Scheff's empirical evidence for this theory led to a published debate as he relied too heavily upon the assumption that individuals with low socioeconomic status are more susceptible to labelling effects than high socioeconomic status. He measured labelling effects by rates of hospitalisation based upon this assumption. However critics argued that hospitalisation can be affected by socioeconomic status through other means, calling into question the theory's validity (Pasman, 2011).

Nevertheless, the notion within Scheff's theory that labelling leads to a negative self-concept was thought credible and was captured by Link and colleagues' (1989) Modified Labelling Theory. Modified Labelling Theory proposes that self-concept is mediated by negative coping responses, which cause self-stigmatisation based upon societal stigmatisation. This then leaves individuals susceptible to further mental illness. This deliberately differs from Scheff's theory as it does not assign the power of creating mental illness to a label. The negative coping responses that individuals may use are:

1. *Secrecy* – not disclosing their diagnosis or treatment to others
2. *Withdrawal* – limiting social interaction to those who know and accept their mental illness
3. *Educating others* – teaching others about the mental illness aiming to elicit empathy and understanding

All three reactions assume that the individual will be exposed to stigma if their mental illness is disclosed. Therefore, Link and colleagues, similarly to Scheff, still discuss the negative

consequences for self-esteem and self-efficacy, two concepts that directly relate to self-concept (Link et al., 2001).

Labelling Theory has been influential for understanding stigma associated with labels (Pasman, 2011). It is important to recognise that by labelling a person, it is acknowledging they deviate from essentialist understanding of 'normal' (Vella Gera, 2017). 'Normalcy' is a concept that is central to diagnostic manuals, although difficult to define. Some scholars question who holds the epistemic rights to determine normalcy thereby disputing the medical model framework that a diagnosis is based upon (Begon & Billington, 2019): Lester et al. (2014) advocates that individuals who have diagnoses should determine normalcy. Yet the medical model is the dominant autism discourse (Begon & Billington, 2019; Kapp et al., 2013; Molloy & Vasil, 2004; Waltz, 2008).

Although both Scheff's (1966) and Link et al.'s (1989) Labelling Theories exemplify negative impacts, neither begin to consider the potential positives of a label. Pasman (2011) conducted a literature review considering the consequences of labelling upon self-concept and found significant positives too. Firstly, some individuals may experience relief as a diagnosis acknowledges their experienced difficulties; this is positive for self-esteem as they then have a reason for 'unusual behaviour'. Secondly, labels allow individuals to receive the correct treatment, increasing self-esteem and self-efficacy, and improving self-concept. Thirdly, a label creates a common language which potentially increases empathy and understanding.

Therefore, Labelling Theory and Modified Labelling Theory can be used to understand different individuals' negative reactions to diagnosis. However, there are also potential positives discussed by Pasman (2011) that should not be overlooked.

2.4 Autistic Community

Autism can be defined as a neurodevelopmental disorder; however this is not the understanding of autism that everyone subscribes to. Individuals diagnosed with autism will go through a sense-making process to understand the significance of the label for them and their identity. A person may identify with autism on a personal or social level, both, or neither (Macleod et al., 2013; Mogensen & Mason, 2015).

There have been a number of autistic individuals who have actively resisted the prevalent stereotypes that exist around their diagnosis (Davidson & Henderson, 2010) and that advocate for autism to not only be defined by deficits, but also the positives (O'Neil, 2008). These advocates are usually proponents of the Neurodiversity Movement that construct autism as a variation of

human functioning, not a disability (Begon & Billington, 2019; Jaarsma & Welin, 2012). This discourse encourages celebrating autism as a positive identity beyond medicalised diagnostic boundaries (Huynh, 2017) and understanding it as an inseparable to identity (Begon & Billington, 2019). Largely credited to increasing internet availability, this movement has supported the development of a sense of community and autistic social identity (Brownlow & O'Dell, 2006). There is a recognised emotional component to the need-to-belong (Baumeister & Leary, 1995; Maslow, 1943) which promotes the sense of community found for some autistic individuals in identifying with the wider Autistic Community. Nevertheless, even when an individual adopts an autistic social identity, this does not automatically imply that this defines their personal identity (Begon & Billington, 2019). It is dependent upon the individual as to how much they wish to explore and commit, as Marcia's Identity Status Theory and Social Identity Theory suggest.

There is also emerging evidence suggesting that less identification with the Autistic Community and rejecting autism as part of one's identity could negatively affect an individual's mental health; thus a positive autism social identity is protective (Carrington & Graham, 2001; Cooper et al., 2017). However, Jaarsma and Welin (2012) note that the Autistic Community may only be accessible to those who are highly verbal e.g. diagnosed as high-functioning or with Asperger's.

2.5 Female Autistic Identity

For many autistic females the process of being diagnosed has been long and challenging (Baldwin & Costley, 2016; Bargiela et al., 2016; Cridland et al., 2014; Kirkovski et al., 2013; Kock et al., 2019) and many will have received diagnoses of other mental health conditions before autism (Bargiela et al., 2016). Furthermore, females are more likely to have received a later autism diagnosis than males (Bargiela et al., 2016; Kirkovski et al., 2013; A. Webster & Garvis, 2017). This has implications for their support, which can impact identification with their diagnosis (Kock et al., 2019; Logsden, 2010). Yet, identification with an autism diagnosis is an individual journey, one that is variable and culturally dependent (Begon & Billington, 2019).

2.5.1 Reactions to Diagnosis

There are many different and complex reactions to receiving an autism diagnosis which can depend upon the meaning the individual attributes to the label and the support they receive (Kock et al., 2019). The meaning they hold will also be mediated by multiple factors in their context such as their age at diagnosis, previous negative life experiences and of pre-diagnosis services, their personal beliefs about the diagnosis, as well as cultural and societal perspectives (Punshon et al., 2009). Receiving an autism diagnosis can lead to a significant shift in how an individual sees

themselves (Leedham et al., 2020). A range of emotions have been described by different females such as relief, anger, confusion, comfort, pride, anxiety, denial, validation and feeling ashamed (Baldwin & Costley, 2016; Feist, 2013; Haney & Cullen, 2017; Leedham et al., 2020). A. Webster and Garvis' (2017) 10 Australian participants described a time of adjustment following their diagnosis within which they reflected, readjusted, and some experienced depression. Similarly, many of Leedham et al.'s (2020) 11 participants described this time as a grieving process. Following this, both sets of participants described how reading autistic literature and about other autistic females supported them to understand autism as a new sense of identity and give them autonomy in the sense-making process; highlighting the self-constructive process that occurs. This would be captured in Marcia's theory as exploring an alternative identity before committing. Significantly, all participants in both studies were diagnosed as adults which may have changed their sense-making as: (1) they will have consented to seeking a diagnosis as opposed to a parent and, (2) they have passed the typical age for identity formation (Erikson, 1968), therefore this may affect how they make sense of a potentially identity-changing diagnosis (Kapp et al., 2013). Mogensen and Mason (2015) investigated how autistic teenagers negotiate their identity incorporating their autism diagnosis. Although they had a mixed gender sample, two female participants revealed differences in sense-making of their diagnoses. One participant, aged 18, found receiving a diagnosis at 8 years old as oppressive. For her, it highlighted differences she was previously unaware of and she received sudden and intense unwanted intervention. Contrastingly, another participant aged 16, found her diagnosis (received 3 months earlier) liberating, giving her more control. An autism diagnosis allowed her to integrate her newfound knowledge into her life and explain some of her past experiences of feeling different. However, she felt she would have benefitted from knowing earlier. Both participants came to accept autism as part of their identity, but interestingly did not disclose it to peers for fear of being treated differently.

Receiving an autism diagnosis appears to offer many females a new sense of themselves; it is often described as a useful framework within which to understand their previous difficulties or differences (Baldwin & Costley, 2016; Feist, 2013; Haney & Cullen, 2017; Kanfiszer et al., 2017; Kock et al., 2019; Leedham et al., 2020; Logsden, 2010) aligning with Pasman's (2011) positive labelling consequences. Yet it can be coupled with pain and sadness for not understanding themselves earlier (Leedham et al., 2020). Reports from Leedham et al.'s (2020) participants highlight how there is a progression from self-criticism to self-compassion to reach a point of self-

acceptance. Nevertheless, there are also females that reject their diagnosis and do not identify with it such as Logsden's (2010) participant, who will be discussed later.

2.5.2 The Impact of Others

Other people can also be highly influential upon a female's reaction to diagnosis. Feist (2013), Gaffney (2017) and Rainsberry's (2016) dissertations all discuss how their participants' relationships with peers and parents impacted how they accepted their diagnosis. Autistic women explicitly reflect that if others accepted them, inclusive of their diagnosis, validating them as individuals, they were more likely to accept and identify with their autism (Leedham et al., 2020). Contrastingly, in Edwards' (2012) dissertation case study, 'Katie' discussed always trying to be nice to others but accepting when they were not her friend, indicating that she accepted herself regardless of others. Edwards concluded "her attitude came from her strong sense of herself" (p. 57). Having a strong self-concept can be a protective factor against internalising difficulties (Jamison & Schuttler, 2015). However, it is not discussed how Katie developed her strong sense-of-self as this may be from being accepted by a few significant people as opposed to everybody. Having a strong sense-of-self despite peer rejection was also discussed by Gaffney (2017) who reflected some of her participants were successful at this, but not all.

Moreover, others' perceptions of autism are not always positive (Treweek et al., 2019). Bargiela and colleagues (2016) spoke to 14 late-diagnosed autistic women in the UK and one theme that emerged was *"you're not autistic"* capturing experiences of others disbelieving their diagnosis. Reportedly, some friends, family and medical professionals had ignored, misunderstood or dismissed their concerns. Some suggested that stereotypes such as 'Rain Man' were unhelpful as they either reinforced that autistic individuals had severe social communication difficulties and/or savant abilities in maths and science, a sentiment also discussed by Leedham et al.'s (2020) participants. One of Gaffney's (2017) adolescent participants reflected when she encountered others questioning her diagnosis it left her confused and questioning it herself. Macleod et al. (2013) acknowledged upon diagnosis individuals must navigate a complex picture of stereotypes, academic debate and media portrayals, all of which may influence how positively or negatively an individual perceives autism. Feist's (2013) US participant 'Jessica' struggled to fully identify with her autism which was attributed to the reactions of her peers upon disclosing her diagnosis. Jessica internalised their reactions incorporating them into her self-concept. The two other participants in Feist's (2013) research were able to resist some negative reactions they experienced because of their creative strengths and interests, which were alternative positive personal identities. Nevertheless, all three participants reflected upon unhelpful autism

stereotypes which can lead people to disbelieve their diagnosis and dismiss their difficulties, causing frustration. These unhelpful stereotypes have been reported in both UK and US research demonstrating it is not a unique localised concern.

Feist (2013) used Social Comparison Theory (Festinger, 1954) to understand the impact of peer reactions upon her participants' identification with their diagnosis. It is important that an individual is not making unfair upward comparisons of themselves which leads to emotional distress, as was seen in Jessica. However Jessica was the youngest participant and was still attending school, which can intensify the importance of peer relationships (P. Smith, 2016). Another effect of not feeling accepted by peers is then the increased motivation to camouflage to appear 'normal'. This both hides and internalises difficulties making it harder to maintain an authentic identity (Hull et al., 2017), possibly further hindering identity development. This is supported by Cook et al.'s (2018) finding that adolescent autistic girls within specialist provisions camouflaged less than those in mainstream settings. This finding highlights the importance of having opportunities to connect with other autistic individuals of similar ability to enable fair comparisons and experience validation and normalisation of autistic traits.

Considering the negative or disbelieving reactions of others, a female may find it more difficult to accept her diagnosis and may be confused and question what sense she can make of it within her own context. The adult autism literature suggests that when others are not accepting of the individual as an autistic person, the individual experiences higher rates of stress, depression and camouflaging (Cage et al., 2018). This sentiment is well captured in Milner et al.'s (2019) theme of *girls can be autistic too!* which discusses the need for more awareness and knowledge about autism to challenge incorrect stereotypes. Specifically, one of Leedham et al.'s (2020) adult participants discussed how her father rejected her diagnosis claiming that there is nothing 'wrong' with her, therein implying that to have autism was to be 'wrong' and imperfect. This individual also described having difficulty integrating autism into her identity; the authors suggest it is perhaps through fear of judgement and invalidation from society based upon her experience with her father.

2.5.3 The Sense-Making Process and Identity

Autistic female research is growing and becoming increasingly phenomenological in nature. In some research, identity is discussed particularly in relation to new identities post-diagnosis (Baldwin & Costley, 2016; Bargiela et al., 2016; Feist, 2013; Hull et al., 2017; Kanfiszer et al., 2017; Kock et al., 2019; Leedham et al., 2020; Logsden, 2010; A. Webster & Garvis, 2017). Molloy

and Vasil (2004) conducted a narrative inquiry into the identity and sense making specifically of adolescents with Asperger's. Although they did not focus on females alone, they had two female participants, Rachel and Sarah. Rachel was 15 years old who was diagnosed as a 4-year-old, but was unaware of her diagnosis until three years later. The authors note that Rachel had previously experienced depersonalisation by adopting an Asperger's identity and seeing herself as the 'embodiment of Asperger's'. This became problematic for her identity exploration. Therapy encouraged Rachel to overcome this by exploring alternative identity roles based upon her interests. Subsequently, Rachel developed a personal identity centring around her heightened intelligence, which she positively attributed to her Asperger's. Thus, she adopted Asperger's as part of, but not her sole identity. The second female, Sarah was 12 and was diagnosed at 11 years old. She had previously been diagnosed with speech and language disorders, dyspraxia and Attention Deficit Hyperactivity Disorder. Her autism diagnosis had been quite recent to her participation, but she reflected upon it positively explaining that it gave her a reason for some of her challenges. One of the greatest challenges Sarah spoke about was her difficulty making friends. She had developed imaginary friends who were animals, in lieu of real friends. For Sarah, having a diagnosis allowed her to develop effective coping strategies in therapy to support her feelings of anger and aggressive behaviours. Interestingly, for Sarah her father did not agree with her autism diagnosis. However, it seems that Sarah found enough value in the diagnosis herself that her father's opinion did not affect her association with the diagnosis. For both Rachel and Sarah, they used their diagnosis to make sense of their past experiences, but also to inform their identity. Yet for Sarah, with previous diagnoses to also negotiate, this was more confusing. Furthermore, Rachel's diagnosis acted as a limiter on her identity exploration for a time. Molloy and Vasil's research offers a fascinating insight into the identity of adolescents with Asperger's. Their two female participants in particular can inform the current research, nevertheless, they did not explicitly discuss identity theory, or what psychological frameworks they were applying.

There are only a handful of studies that have explicitly applied identity theories focusing upon female autistic participants to offer insight into their sense-making processes. Logsden (2010) and Feist's (2013) dissertations applied Erikson's and Marcia's theories to understand the sense females make of their diagnosis and what their influential experiences were; these will be discussed in detail below.

2.5.3.1 Logsden (2010). Logsden explored adolescent experiences and identity development for American women with Asperger's using a mixed-methods approach including a Likert response questionnaire and structured interview. For two of the three participants it was

clear that experiencing a sense of belonging was vital for their self-acceptance and identification with their diagnosis. One participant, ‘Amber’ discussed her poor mental health and self-harming prior to attending a more structured school with more accepting peers. Subsequently, Amber was more accepting of her diagnosis and normalised it by saying “everybody is Aspie in a way” (p. 47). Logsden considered Amber to represent ‘identity achieved’ status (Marcia, 1966) as she was proud of her own opinions whilst being open to hearing others; she also embraced her Asperger’s and had a positive self-concept. Another participant, ‘Beth’ discussed how she felt safe and accepted within her Special Education classes, however when in the wider mainstream school, this changed. Beth also discussed struggling to adjust to changes in routines or relationships which led Logsden to conclude that she represented ‘identity foreclosure’ status. Although, arguably these are clinical features of an autism diagnosis. Therefore, the accuracy of this conclusion is questionable, and Marcia’s theory should be applied with caution as some specific behavioural characteristics may differ between individuals.

The third participant, ‘Julie’, had a contrasting experience. When Julie was diagnosed with Asperger’s her mother rejected the diagnosis; she thought Julie was copying her older brother who was Aspergic. Interestingly, even Julie did not describe herself as Aspergic; thus, she did not identify with the label. Julie described that during her adolescence she did not meet behavioural expectations: she engaged in minimal social interactions, dressed more masculine, and was not heterosexual. These behaviours led to suggestions from family members to change these aspects of herself, they did not accept her for who she was. Logsden considered Julie to represent ‘identity diffused’ status due to confusion about herself; low self-esteem, and low motivation to explore identity roles further.

Importantly, the two participants that received the most intervention had the best understanding and acceptance of themselves and their Asperger's. Furthermore, the age at which they were diagnosed corresponded with when they began to receive therapeutic input. A further interesting finding was that the number of books participants had read about others’ experiences of Asperger's related to how accepting and aware they were of their own Asperger’s.

Logsden’s participants demonstrate that the identification with an autism identity is dependent upon the experiences, support and information received post-diagnosis. Although Logsden did not apply Social Identity Theory, its application here is relevant as it demonstrates that the information and support for exploring autism correlated with how positively they identified with an

autism identity. These findings have implications for the timely diagnosis of autistic girls to offer them maximum opportunity and time to access support.

Logsden's research offers insight into how these Aspergic women accepted their diagnosis and what experiences and relationships influenced their perspective. However, this research was asking adults to reflect upon their adolescence; therefore, it may not be an accurate representation of how they were thinking and feeling as adolescents.

2.5.3.2 Feist (2013). Feist applied identity theories to explore the identity and sense-making of autistic adolescents. YouTube videos by three adolescent Aspergic girls were analysed: two from the US and one from the UK. As the videos were created during adolescence Feist was able to access a more accurate representation of the adolescent perspective than Logsden's research. Again, all of Feist's participants were diagnosed with Asperger's, but they used the terms autism or 'ASD' interchangeably.

Two participants, 'Johanna' and 'Sarah', communicated acceptance of their diagnosis explaining it enabled them to make sense of their difficulties, as Pasman (2011) concluded is a positive labelling consequence. Johanna's diagnosis gave her an understanding of her differences, whilst not changing or interfering with her aspirations and interests in life. Thus, receiving the diagnosis did not cause any dissonance with her pre-formed identity meaning her exploration closely aligned with her current understanding of herself. She both explored and committed to her Asperger's diagnosis. Similarly, Sarah accepted and committed to her diagnosis. She described previously experiencing dissonance with other mental health diagnoses, however when Asperger's was diagnosed, she "just felt a lot more comfortable" (p. 71). Sarah also discussed having a close and meaningful relationship with her boyfriend that supported her self-acceptance, as she had struggled beforehand. Feist reflects that both Johanna and Sarah had previously had a sense that they were not 'normal'. When diagnosed they found a category they *did* fit, allowing them to accept themselves. Although Feist did not explicitly apply it, this aligns with Social Identity Theory: through diagnosis they found similarities within a social category and then identified and aligned with the group.

Feist's third participant 'Jessica' also found a sense of meaning and explanation with her diagnosis, however Jessica did not always perceive it positively. She is described as struggling to come to terms with the role of Asperger's in her life. Jessica was in a "constant flux of association with and dissociation from her diagnosis" (p. 73) and referred to it both as a part of

herself and as a separate entity. Feist concludes for Jessica: “her peers’ responses to her have affected her ability to accept her ASD” (p.55). Jessica still seemed to be exploring what her diagnosis meant and had not resolved her identification with it shown by her also expressing a desire to be autism-free.

Feist discusses the different reactions to her participants’ diagnoses depended upon how they frame autism, whether as a ‘disability’, or a ‘difference’ with good qualities. As Labelling Theory would suggest, their concept of autism depends upon their exposure to autism prior to diagnosis. The three girls were active in trying to reconstruct their own understanding of autism and Asperger’s as vloggers; but they demonstrated differences in exploration and commitment. Two participants were interpreted as advocating for autism to be viewed as a difference as opposed to disability, aligning with the Neurodiversity Movement. For them, being able to adopt this perspective may have been advantageous for their autism identity. It would be interesting to consider if identification with their diagnosis or their perspective came first, which would have implications for the labelling theories. However, this was beyond the scope of Feist’s retrospective analysis of YouTube videos meaning she did not have opportunity to interact with participants or explore any lines of inquiry beyond what was posted.

2.6 Relevance to Educational Psychology Practice

As previously mentioned, there is a need for better teacher awareness of autistic girls, and specifically how school life can be impacted (Baldwin & Costley, 2016; Goodall & MacKenzie, 2019; Jarman & Rayner, 2015; Moyse & Porter, 2015). With current knowledge and training, a large majority of teaching staff are not equipped to support this cohort (Jarman & Rayner, 2015). EPs are able to support systemically through whole-school training incorporating their evidence-based knowledge to combat this (Such, 2017).

Concerning the individual level, some teachers do not adapt their classroom practice even when parents provide information (Jarman & Rayner, 2015). This perhaps contributed to the 46% of the autistic females that cited ‘lack of support’ as one of three worst things about school (Baldwin & Costley, 2016). However, some teaching staff do respond to the needs of autistic girls, and importantly the research highlights successes too (Baldwin & Costley, 2016; Cresswell & Cage, 2019; Edwards, 2012). EPs can support inclusion of autistic girls within schools; this especially includes facilitating the perspective that support may still be necessary in the absence of academic needs (Baldwin & Costley, 2016; Jarman & Rayner, 2015; Moyse & Porter, 2015; Such, 2017; Tomlinson, 2019). It is also important for EPs to help schools to create individualised

support plans (Baldwin & Costley, 2016; Jarman & Rayner, 2015; Such, 2017) incorporating the girl's views (Gaffney, 2017; Mercieca & Mercieca, 2014). By gathering the views of the young person, their reality can be understood and adjustments made accordingly (Begon & Billington, 2019).

Another possible contribution of EPs is providing therapeutic input (Roffey et al., 2016; Such, 2017). Feist (2013) and Cresswell and Cage (2019) for example discuss the potential for psychologists to support the identity exploration of autistic girls, helping them recognise strengths and talents to explore their personal and social identities. It could be important to help reframe their understanding of autism as a difference not a disability, in line with the Neurodiversity Movement (Feist, 2013), as some research indicates this is supportive for psychological wellbeing (Carrington & Graham, 2001; Cooper et al., 2017).

A further contribution is research (Such, 2017; Topping & Lauchlan, 2013). EPs are well-placed with their research skills and educational practice to use empirical means to capture what is helpful or not for supporting autistic girls. For example, Such's (2017) dissertation which investigated EPs' role in supporting adolescent girls with social communication difficulties contributed to the development of *The ASD girls' wellbeing toolkit: an evidence-based intervention promoting mental, physical and emotional health* (Rae & Such, 2019).

It is also notable that in some local authorities, EPs also form part of the multi-professional team that diagnose autism. Therefore, there are many different ways that EPs have the potential to support autistic girls, the knowledge gained from research is very relevant to their practice.

2.7 Conclusions About the Literature

Research into the female experience of autism is a growing area of interest, as can be seen by the recency of much research in this review. However very few consider the impact upon identity by applying psychological theory and using phenomenological approaches. There is a dearth of literature especially within the UK and speaking to adolescents when they are adolescents. Thus, adolescent autistic girls' perspectives are not well understood. Considering that autistic females have been identified as a minority within a minority (Beteta, 2009) it is important to directly understand adolescent autistic females' perspectives and not assume that research with autistic males or adolescent girls will suffice as the intersectionality of these features may be quite unique. It is also important to recognise that this is a dynamic topic with diagnostic boundaries and current understanding changing, particularly for autistic females. Thus, there are many important areas

to still explore in the realms of the autistic female experience and one piece of research cannot address them all. This research will investigate the narratives of adolescent autistic girls to explore their understanding of and identification with their autism diagnosis. It is only through listening to autistic girls' personal experiences that professionals, such as EPs, can then effectively support them.

2.8 Research Questions

Therefore, as a result of critically reviewing the literature, this dissertation's research questions are:

1. What do adolescent autistic girls' narratives reveal about how they understand and identify with autism?
2. What are the influential experiences and relationships that adolescent autistic girls talk about that affect their identification with their diagnosis?

3 Methodology

This chapter describes the methodology chosen for this research. The research aims and questions will be reiterated before the decision-making steps taken towards choosing the methodology will be outlined. Next, my philosophical position will be presented before Narrative Inquiry will be discussed in more detail. Subsequently, the research design will be described covering ethical considerations taken, recruitment methods, interviewing, and visual supports used. Also included in this chapter is a discussion on researcher reflexivity. Finally, the approach taken to data analysis will be outlined.

3.1 Aims of This Research

This research aimed to explore the subjective experiences of adolescent autistic girls to consider how they understand their diagnosis and what experiences or relationships may have influenced their identification with their autism. This research also aimed to understand and raise awareness of adolescent autistic girls' experiences by capturing a variety of girls' narratives.

The research questions being explored were:

1. What do adolescent autistic girls' narratives reveal about how they understand and identify with autism?
2. What are the influential experiences and relationships that adolescent autistic girls talk about that affect their identification with their diagnosis?

3.2 Qualitative Research

The nature of the research aims indicated that qualitative research would be most suitable to capture subjective experiences and perspectives. Quantitative methods would not have been appropriate due to the deductive nature and objectivist ontology (Bryman, 2012) which do not align with the research aims. As such, the philosophical underpinnings of quantitative research do not fit this dissertation.

It is essential when conducting qualitative research to consider how to demonstrate and assure the research's validity and rigour, which differs from quantitative (B. Smith, 2018; Yardley, 2015). Yardley's (2000, 2015) criteria to demonstrate validity in qualitative research was used. Therefore, the sensitivity to context, commitment and rigour, coherence and transparency, and, impact and importance of this research has been considered throughout. An evaluation of the quality of this research can be found in the Discussion chapter.

3.2.1 Qualitative Methodologies

As this research intended to better understand adolescent autistic girls' meaning and experience of their diagnosis, Grounded Theory, Interpretative Phenomenological Analysis (IPA), and Narrative Inquiry (NI) were considered, as these methodologies aim to understand meaning and experience through different means (Ritchie et al., 2013).

Grounded Theory was considered, however as it is an iterative approach aiming to develop a theory by capturing the new understanding revealed (Bryman, 2012), it was not appropriate; the current research did not have the main intention of developing a theory. Thus, Grounded Theory was discounted and IPA and NI were considered next.

3.2.2 Interpretative Phenomenological Analysis

Both IPA and NI adopt a person-centered, humanistic approach that is grounded in post-modernist ontology. Both are also interpretative and use first person accounts (Griffin & May, 2012); all features that align with the current research aims. Nevertheless, despite the number of similarities between IPA and NI, there are also differences which influenced the final decision.

IPA is a methodology based within its own philosophy of phenomenology, understanding a person's lived experience through their consciousness; and hermeneutics, acknowledging the researcher is reconstructing the person's perspective that they co-created (Eatough & Smith, 2017). IPA analysis is an iterative process that aims to get close to individual experience (Griffin & May, 2012) by recruiting homogeneous cohorts to investigate similarities and differences. Following analysis, a new theory or understanding is generated (Alase, 2017). In this sense it aims to create a universal understanding of the lived experiences of a homogenous cohort. This can be useful for a number of topics, and has been used in autistic female research (e.g. Cridland et al., 2014; Haney & Cullen, 2017; Leedham et al., 2020; Tierney et al., 2016). Nevertheless, the current research does not share this aim. Instead, this research is exploring individual experiences to capture the diversity and variety, whilst highlighting the heterogeneity within a population that are often presented as homogenous; features that NI allows for more so than IPA. Consequently, NI was well suited as will be further detailed in Section 3.4, however first, my epistemological and ontological position will be explained.

3.3 Research Philosophy

Before undertaking a discussion about NI as an approach, it is important to first consider the philosophical position of this dissertation and of myself as a researcher, as this will also aid understanding of the methodological decision.

Traditionally much research with autistic females has been based upon a positivist epistemology trying to discover the defining features and characteristics of the 'autistic female phenotype' which have contributed to our current understanding of autism. Yet, there could also be considered problems with this approach as it aims to uncover the 'one truth', which is reductionist and assumes predictive generalisability as an aim (Guba & Lincoln, 1982), as well as ignoring autism's social construction. Instead, I understand reality and knowledge as part of the interpretive paradigms adopting an inductive, rather than deductive, approach to research (Goldkuhl, 2012). Specifically, my research is based within a social constructivist paradigm, adopting a subjective epistemology and relativist ontology. These philosophical positions match my personal and professional approach to working with autistic females whilst aligning with my Critical Autism perspective, understanding that multiple versions of autism exist (Begon & Billington, 2019).

A social constructivist paradigm understands that an individual is active in interpreting their world based upon their social context. They access this understanding through interaction with others. Social constructivism is based upon a relativist ontology, where ontology is defined as the theory of being (Denzin & Lincoln, 2011). A relativist ontology understands multiple realities exist dependent upon subjective experience, co-construction of reality, and individual sense-making (Goldkuhl, 2012). Therefore, there is a world of events external to human consciousness. It is by individuals observing and interpreting those events situated within their historical, cultural, and social context, that they construct their reality.

Epistemological considerations are ones that consider how legitimate knowledge about the world can be gained (Stainton-Rogers & Willig, 2008). A subjective epistemology understands that knowledge is created through the process of interaction between participant and researcher who aims to share their reality. Therefore, each individual's experience and interpretation is unique and it cannot be assumed to translate to others, even if, for example, they share the same diagnostic label. Individuals' subjective experiences are value-bound and idiosyncratic, therefore holistic inquiry is necessary (Goldkuhl, 2012; Guba & Lincoln, 1982). Narratives can be used to communicate subjective experiences (Murray, 2015). When there is a concrete event shared by individuals, such as receiving a diagnosis, it is valuable to compare subjective interpretations for consensus or discrepancies across realities to learn from them (Guba, 1990, as cited in Denzin & Lincoln, 2011).

These philosophical positions led me to adopt a hermeneutical methodology to elicit individuals' constructions. NI was selected as this will allow understanding and interpretation of the meaning and reality of autism to individual participants (Denzin & Lincoln, 2011) through co-constructed

narratives (Muylaert et al., 2014). This will also provide the participants with a platform upon which to share their own experiences.

3.4 Narrative Inquiry

NI is an approach that holistically considers narratives co-constructed between researcher and participant (L. Webster & Mertova, 2007). NI does not aim to generalise across participants, meaning that it is well suited when considering a heterogeneous group, although conceptual generalisability may be possible. NI also remains sensitive to individual context, an important quality assurance of qualitative research (Yardley, 2015). NI researchers can take a more removed role through narrative interviews, giving the participant more control over what direction the conversation takes (Muylaert et al., 2014; Riessman, 2008). NI is an approach that interprets the meaning and the sense-making of participants based upon the assumption that the narratives shared are reflective of participants' thought processes (Lieblich et al., 1998; Polkinghorne, 2007). Consequently, NI is an appropriate research methodology.

3.4.1 Narrative Interviews

Narrative interviews are the most common method used to gather narratives (Squire et al., 2014); they are typically unstructured and can be described as more of a conversation. They aim to use the everyday communication method of storytelling to structure the conversation (Jovchelovitch & Bauer, 2000). The researcher facilitates the participant sharing their narrative through comments and questions encouraging elaboration (Muylaert et al., 2014). Researchers remain sensitive to participants' context (Murray, 2015) especially through reflecting back their language (Jovchelovitch & Bauer, 2000). Narrative interviews do not assume that the narrative shared is an exact recounting of events, instead it allows for, and relies on the fact that, some events are deliberately or unconsciously forgotten (Muylaert et al., 2014). It is, therefore, the salient events and memories that are narrated within the interview that have shaped the narrator's understanding and sense-making. As such, narratives are understood as participants' interpretation of their lives and cannot be judged as 'true' or 'false' (Jovchelovitch & Bauer, 2000) as realist studies would. Therefore, triangulation to ensure credibility was not appropriate.

Nevertheless, there are limitations to narrative interviews. Firstly, the expectations of participants will influence what they choose to share with the researcher as participants may tailor their narrative to what they think the researcher wants to hear (Jovchelovitch & Bauer, 2000). I brought this awareness to the analysis acknowledging that the narratives constructed are hermeneutic in nature and cannot be separated from the context within which they were co-constructed and had

purpose (Riessman, 2008). The participants in my research would not be creating their narratives if I had not been conducting this research and opened that conversation.

A further limitation of a narrative interview can be that the researcher is meant to be a naïve listener and 'play ignorant' to avoid any assumed knowledge or understanding (Jovchelovitch & Bauer, 2000). However, there are often difficulties with this, and specifically for my research, participants and families were aware that I was a TEP and this research was contributing towards my doctoral qualification. Thus, they are likely to have preconceived ideas of what I already know, and may alter their narrative accordingly.

Furthermore, notably I am using interviews with a population that are typically considered to have social-communication difficulties. However, a number of research projects have been conducted about engaging autistic individuals in research (e.g. Beresford et al., 2004; MacLeod, et al., 2014; Tyrrell & Woods, 2018) demonstrating that with appropriate preparation and adaptations, autistic individuals can participate fully in the research process. Thus, adaptations can make the process inclusive, facilitating the opportunity for their voice to be heard through an interview format. Specific considerations and options I offered participants are explained in Section 3.5.

Thus, NI was considered an appropriate methodology for the current research's aims, and the narrative interview the method to conduct the inquiry.

3.4.2 Defining Narrative

Narratives have long been considered important to humans and as integral to culture(s) as they share knowledge through myths, histories and stories (Atkinson & Delamont, 2006; Murray, 2015; Riessman, 2008). Everything humans experience is made sense of in terms of 'time' and 'sequence' (Crossley, 2002) and narratives are a linguistic tool through which this can be expressed (Murray, 2015). As Hursserl describes, we cannot encounter events in isolation; the context of what has gone before and the sense made, is important (Crossley, 2002).

Despite narratives often being recognised as important, it is a concept that does not yet have a unified definition (Clandinin, 2016; Georgakopoulou, 2006; Riessman, 2008; Squire et al., 2014). The definition adopted can vary depending upon epistemological position (Squire et al., 2014) meaning narrative itself can be operationalised and analysed differently (Riessman, 2008). For this dissertation, the definition used is provided by Murray (2015) who described narratives as "an organised interpretation of a sequence of events" (p.87). Narratives also "provide structure to our very sense of selfhood" (p.89) highlighting that individuals can be active in creating their own narrative identity. The notion that narrative is important and worthwhile to study is because: "there

are assumed to be individual, internal representations of phenomena – events, thoughts and feelings – to which narrative gives external *expression."* (Squire et al., 2014, p.5).

Within narrative research there are two main 'camps' of researchers, the narrative inquirers and the narrative analysts. Georgakopoulou (2006) describes the distinction as narrative inquirers use narratives as a method to understand what stories can reveal about the narrator, while the narrative analysts aim to understand how narratives are created and shared. The two 'camps' are not dichotomous and, particularly for studying identity, both approaches are important (Georgakopoulou, 2006). As will be seen in Section 3.7, both can be synthesised to offer in-depth analysis of narratives.

3.4.3 Using Narratives to Explore Identity

Importantly for this research, narratives offer a way to understand identity. McAdams (2008) describes narratives as both constructed to communicate and make sense of the world, but also as being crucial to our understanding of ourselves. Narrative is a form that allows us to both align and distinguish ourselves from others by creating narrative identities, defined as "an individuals' internalised, evolving and integrative story of the self" (McAdams, 2008, p.242). Murray (2018) also notes that multiple narrative identities can exist as each serve a function in different contexts. It is possible one or more narrative identity may be a collective identity, which conceptually links to Social Identity Theory introduced in the Literature Review.

It is also important to note that narrative identities are dynamic and respond to changes in personal and social context (Murray, 2015) since how we communicate the narrative is influenced by both conscious and unconscious social and psychological forces (Hollway & Jefferson, 2000, as cited in Murray, 2015). As NI focuses on understanding experience (Clandinin & Connelly, 2000), analysing narratives enables understanding of people's own self-identification (Murray, 2015). Thus, through analysing adolescent autistic girls' narratives, an understanding of how they both make sense of their autism and formulate their identity can be interpreted.

3.4.4 Narrative Oriented Inquiry

NI itself does not have a prescribed method of analysis, there are many options available to narrative researchers (Riessman, 2008; Squire et al., 2014). The approach taken, similarly to the narrative definition adopted, will depend on the epistemological position and what researchers believe can be understood from a narrative. Different options were considered for this research including thematic, structural, and dialogic analysis (Riessman, 2008), the Listening Guide

(Gilligan, 2015) and Narrative Oriented Inquiry (NOI; Hiles et al., 2009). Due to its alignment with my epistemology, and the comprehensive nature of the analysis, I adopted NOI.

NOI allows for exploration of narratives with a psychological focus. It is noted that the NOI model is still “a work-in-progress” (p.152) and it is not a prescriptive staged process, but instead a dynamic framework for good practice (Hiles et al., 2010). NOI is an approach developed from combining previously well-renowned narrative analysis and literary theory such as Lieblich et al., (1998), Emerson and Frosh (2004) and Herman and Vervaeck (2001). The model was created out of dissatisfaction with the available analytical approaches; Hiles and Čermák thought there was an extra element that was overlooked, that of Riceour’s *narrative intelligence* (Hiles et al., 2010). Consequently, NOI was developed to capture the aspects of both structural and content analysis using established approaches whilst also contributing an additional dimension to access narrative intelligence.

Notably, NOI offers a framework that was appealing as a novice narrative researcher: the distinctive steps guided interpretation and offered structure, contrasting many other forms of NI analysis such as Clandinin's (2016). The stepped process also contributes to the rigour of this research (Yardley, 2015). NOI is a pluralistic and inclusive model (Hiles & Čermák, 2008). It is also flexible and allows for professional judgment of how best to apply the model, one such adjustment will be explained in Section 3.7.5. The transparent nature of NOI also allows for reviewing analysis (Hiles et al., 2010). This afforded me opportunity to ensure I was maintaining a level of consistency, and enabled analysis to be shared with others to check the coherence and transparency of analytical conclusions.

NOI is relatively new. Notably most of the publications endorsing NOI are authored by the creators themselves which means there is an inherent bias. Nevertheless, there are examples of NOI being used within journal articles (e.g. Wang et al., 2017) and especially within Educational Psychology doctoral research such as Ardern (2014), Newton (2014), and Stewart (2017) additionally to other doctoral dissertations: Felix (2013), Rahemtulla (2016) and Spatuzzi (2015) demonstrating its usefulness and applicability. Specifically NOI has been used and demonstrated as a useful approach to understand diagnosis constructions for young people with autism (Samra, 2016); thus, it is appropriate for this research.

Hiles and Čermák (2008) highlight the importance of adopting a NOI approach from a project’s inception including when developing research questions and design. Although my research questions were drafted before selecting NOI, they were subsequently refined. The interview

prompts and visual supports used, which will be shared in Section 3.5.4, were also in-keeping with the approach adding to the coherence of this research. For transparency, the steps of NOI used for data analysis will be described in Section 3.7.

3.5 Research Design

The overall procedure of this research is reflected in Figure 1. Each step of the research and additional resources will be discussed in more detail in Section 3.5.4.

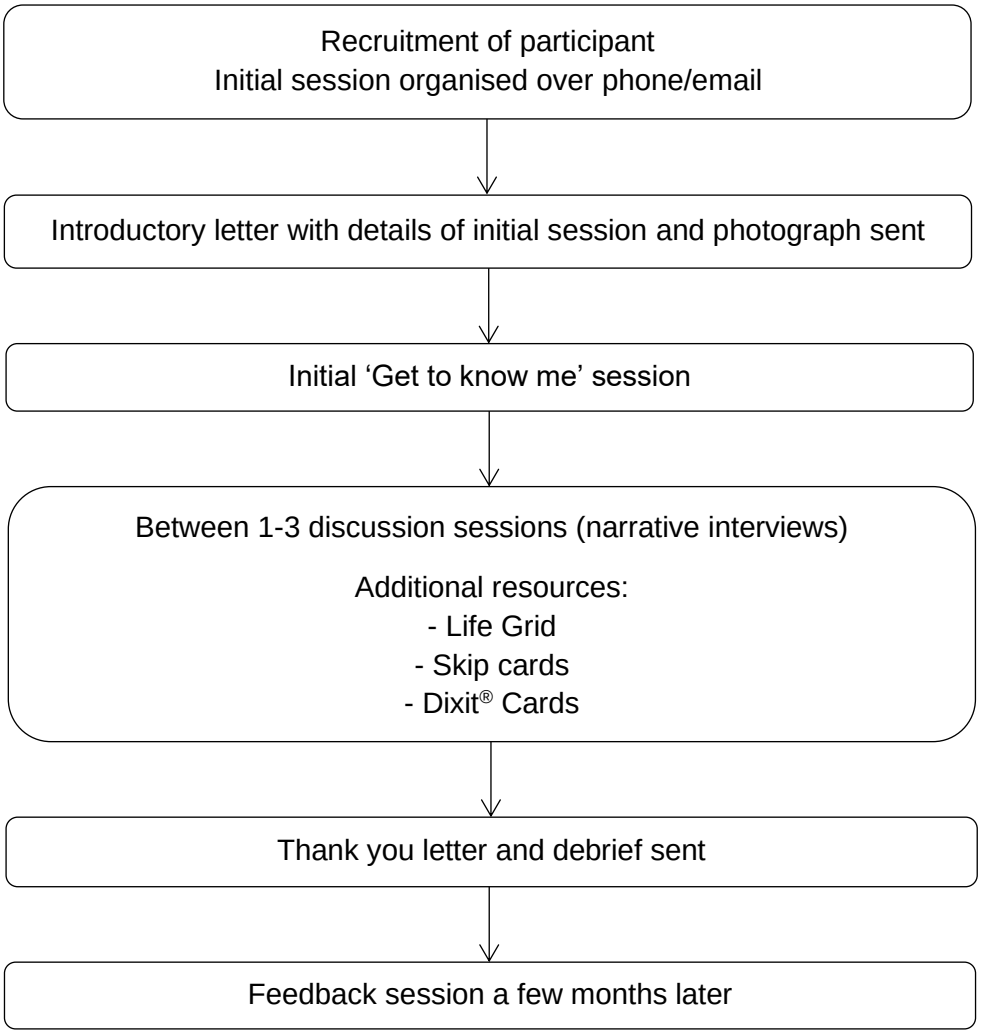


Figure 1. *Overall Procedure.* A figure to depict the overall research procedure.

3.5.1 Ethical Considerations

As many decisions about the methods and design were ethically driven, it feels appropriate to discuss the ethical considerations before methods. Ethical considerations need to be made to ensure that the rights and dignity of participants are upheld and respected (British Psychological Society [BPS], 2014). Ethical approval for this study was granted by the University of Bristol, School of Policy Studies Ethics committee (Appendix B).

This study was designed with consideration of participants' research experience whilst also accounting for what is known to support autistic participants. It was important to enable participants to share their stories freely and have their voice heard, honoring their right as stated within the United Convention for The Rights of the Child (UNCRC; UNICEF, 1989) and the Special Education Needs and Disability (SEND) Code of Practice (Department for Education, 2015).

The first ethical consideration to discuss is 'maximising benefit and minimising harm' (BPS, 2014) particularly when considering the sensitive nature of the research topic. A strength of using narrative interviews was that participants had more control over the discussion (Muylaert et al., 2014), thus minimising the chances of distress. Additionally, there was a further benefit to participants in having the opportunity to share their stories to an interested listener, as this can be quite therapeutic (Riessman, 2008). Nevertheless, it was stressed that the sessions were not therapy. If participants anticipated distress or felt uncomfortable, they had continual access to visual cards that asked to 'stop', 'skip' or 'break'. Also, during the initial session, participants were asked what they would like to happen if they became upset. Following sessions, participants were also given a notebook to record any thoughts or feelings. They were assured that this notebook would not be used for analysis, rather it offered them a reflective opportunity if they needed or wanted it.

Secondly, another important ethical consideration was informed consent. Individuals in this research can be considered to be part of a vulnerable population: the majority were children, and they were diagnosed as having social and communication difficulties (BPS, 2014). Therefore, specific considerations were made to ensure that consent given was fully informed. All participants were asked for written consent or assent (Appendix C), and parental consent was gained for participants under 16 years old (Appendix D). Nevertheless, consent was also considered as an ongoing process (Lewis & Porter, 2004) and as such was reestablished at the beginning of discussion sessions, and their right to withdraw was reiterated.

Further thought was given to the imbalance of power in the research especially as this can be a particular issue when conducting interviews (Kvale, 2006). The information sheet emphasised that participation was voluntary and detailed their right to withdraw. Participants were also given choices throughout the process as to where, when, and how many times they would like to meet and how they would like to communicate, to increase their agency. Additionally, they had the option to have someone accompany them during their sessions. With the selection of narrative interviews which are guided by participants and the choices given to participants to increase their control over the situation, the power imbalance was lessened.

Confidentiality and anonymity are particularly difficult with small samples and minority populations. It was ensured that participants were aware of the limits of confidentiality. Furthermore, originally participants were going to create their own pseudonyms; however, this was considered by the Ethics Committee to be a potentially identifying feature if they chose a nickname for example. Therefore, instead participants were asked to select their preferred pseudonym from three popular names in the year of their birth allowing them some control over how they are presented whilst avoiding the risk of identification. All identifying features such as names of people and places were anonymised.

Narrative ownership is a further ethical consideration as a direct result of the chosen methodology. There is a risk that researchers may misinterpret or misrepresent the narratives shared (Riessman, 2008). Therefore, to combat this, three things were done. Firstly, member reflections were completed where preliminary themes were shared with participants during their feedback session (Lewis & Porter, 2004; Tracy & Hinrichs, 2017). Secondly, in Chapter 4 participants' narratives are largely presented using their original words to keep their narrative intact and remain true to their reality. I have also used their preferred terminology for referring to their diagnosis. Thirdly, an accessible research summary will be disseminated to participants.

3.5.2 Autistic Research

Research has been conducted into how best to elicit the views specifically of autistic participants. When designing this research I used these findings with my professional expertise, to make the research experience accessible and comfortable.

Autistic individuals have identified four key barriers to research participation as being (MacLeod et al., 2014):

- Anxieties around communication methods
- Anxieties about the interview process

- Time-management difficulties that affect remembering appointments
- Social communication difficulties which will affect how they interpret questions or are interpreted

Therefore, steps were taken to address these barriers.

Concerning anxieties about communication and the interviews, participants were offered choices of communication methods (talking, writing, drawing or an alternative they preferred) to empower them throughout the process (Tyrrell & Woods, 2018). Furthermore, I minimised the intensity of face-to-face interaction by using visual supports (as will be described in Section 3.5.4) to redirect focus and offer a distraction if needed (Lewis & Porter, 2004; Tyrrell & Woods, 2018). Additional choices about location, number of sessions and an accompanying adult were also offered to reduce anxieties (Lewis & Porter, 2004).

Furthermore, to address concerns about time-management, when booking sessions with participants or their parents/teachers I offered an option of a reminder. Two participants requested a reminder the day before.

When considering the social communication difficulties that may affect interpretation of questions, I used my communication skills developed over years of working with children and young people to communicate effectively. Furthermore, as I adopted a narrative interview process as opposed to structured or semi-structured, there was less need for participants to interpret my questions as there were fewer. The 'stop', 'skip' or 'break' visual cards were also provided to support participants' comfort throughout.

3.5.3 Recruitment and Sampling

A purposive sampling method was adopted recruiting through LA EPs and support groups for autistic girls. EPs were asked to contact SENCos in their schools with the advert (Appendix E) and information sheets (Appendix F & G). SENCos were then asked to either display the advert or share information sheets directly with girls and parents if they thought they may be interested. Notably this relied on the judgement of EPs and SENCos as gatekeepers to consider who to approach, however it also reduced the potential obligation participants could feel if I had approached them directly (Lewis & Porter, 2004). Support groups were contacted asking them to display the advert or pass on information sheets to interested individuals. From this point I relied on potential participants making contact to ask questions and if they were happy to, arrange the initial session.

The only participant inclusion criteria were that they were female, between the ages of 12-19 years old, they had a diagnosis of autism (inclusive of all diagnostic labels) and that they were aware of and happy to reflect upon their diagnosis. Therefore, this meant no participants were excluded due to communication styles, comorbid conditions, type of school provision, ethnicity, socioeconomic status, culture, or any other personal variables, as is often the case in autistic literature.

Seven participants in total were recruited, two of whom withdrew at different stages of the process due to personal circumstances. Ultimately five fully participated ranging in age from 12-18 years old. Introductory paragraphs that participants had opportunity to edit will precede each participant's narrative in Chapter 4 to provide an overview of their personal context.

3.5.4 Procedure for Data Collection

Each stage of the procedure will now be described, referring to the steps depicted in Figure 1.

3.5.4.1 Initial Session. Once potential participants were identified, an initial 'get to know me' session was arranged lasting approximately 30 minutes at their chosen location (home, school or Educational Psychology Service office). This session was used as an introduction to myself and the research. Demographic and preference information was also gathered, such as their preferred method of communication and what terminology they use to refer to their autism. I also showed participants the visual supports and the recorder I would use in the discussion sessions. This session concluded by checking their understanding of the consent form and gaining theirs and, if necessary, their parent's, written consent. Further dates were then agreed for the narrative interviews.

3.5.4.2 Narrative Interviews. The narrative interviews or 'discussion sessions' lasted for approximately an hour each. Verbal consent was re-established at the beginning of each session. These sessions consisted of a conversation with the participant loosely following a Narrative Interview Guide (Appendix H). The interviews started with rapport building and asking participants to describe themselves in three words. Following this, participants were asked to reflect more on their autism and significant experiences and relationships. Throughout, participants were asked questions to expand on what they shared to gain deeper understanding, and to temporally place their experience (Muylaert et al., 2014). The visuals that are described in the following sections were always accessible to participants. At the conclusion of each session, participants could choose whether they would like a further discussion session, up to three.

Following their final discussion session each participant received a personalised thank you letter which also included information about autism groups in the LA.

3.5.4.3 'Stop', 'Skip' and 'Break' Cards. Visual cards to communicate 'stop', 'skip' and 'break' (Appendix I) were permanently available to participants. These were to support participants to communicate their needs if they felt unable to verbalise them and to offer a visual reminder that they had control over the situation.

3.5.4.4 Life-Grid. Life-Grids were originally developed as a visual method to encourage young people to tell their stories by mapping significant events in a temporal fashion (Wilson et al., 2007). Life-Grids have been successfully used by Samra (2016) working with autistic young people. Therefore, I created a Life-Grid to help guide participants' narrative, if needed (Appendix J). The topics included in the Life-Grid were based upon existing literature and were reflective of the topics used for discussion by Molloy and Vasil (2004): home and family; interests, sports, and hobbies; autism and other diagnoses; school; and important relationships. Furthermore, the timeline was demarcated into school key stages as I considered these would be easily distinguishable time-points for participants to reflect upon, whilst offering enough specificity for analysis. It was emphasised to participants that the Life-Grid was available, but they did not need to use it and could discuss other topics. It was suggested that participants might like to fill it in as we were talking or may want to just have it to refer to, or not at all. All participants referred to the Life-Grid to guide their topic of conversation at least once, although no one filled it in.

3.5.4.5 Dixit® Cards. Following the narrative interview, participants were presented with 25 Dixit® cards (Appendix K) and were asked to choose cards that represented what their autism means to them. They were also asked to explain why they chose the card/s, if happy to. The pictures chosen will accompany their narrative in Chapter 4.

3.5.4.6 Feedback Session. A few months after participants' discussion sessions, we met again for a final time as a feedback session. During these sessions, which lasted between 20-45 minutes, several things were fed back. Firstly, a visual that had been created as part of analysis depicting their journey with autism across the years was shared (Appendix L). Within this, significant experiences and relationships they had discussed were included to consider if/how this interacted with their autism. Secondly, key themes drawn from their narrative were also shared engaging participants in a level of member reflection. Furthermore, participants were invited to edit their introductory paragraph to precede presentation of their narrative in Chapter 4 to give them a sense of ownership over how they are presented. Finally, participants were left with both

a copy of the Dixit® cards that they had selected with their corresponding quotes (Appendix M) and a picture that included pertinent quotes they shared throughout their interviews (Appendix N). The purpose of this was to leave them with a memento of their participation. This feedback session also acted as closure for participants to the research process.

3.6 Researcher Reflexivity

Reflexivity is the process within which a researcher engages with examining their personal assumptions, beliefs, and emotions (Hsiung, 2008) which is especially important for qualitative researchers (Hsiung, 2008; Tracy & Hinrichs, 2017; Yardley, 2015). It is by acknowledging the active presence of researchers in their qualitative research that makes the validity of the research transparent, therefore reflexivity can be considered a quality control measure (Cho & Trent, 2006).

Throughout I have engaged in reflexive practices to consider my motivations, influence and personal constructs affecting the research; particularly acknowledging the hermeneutic nature of narrative interviews (Geanellos, 2000). Some reflexive notes can be seen on my working transcripts (Appendix O) however I also engaged in much more thinking beyond these. Notably I was an 'outsider' from the participant group as I do not have an autism diagnosis; therefore I have remained one-step removed from analysis because as an insider there is a risk of projecting your own feelings onto interpretation (Dwyer & Buckle, 2009). Nevertheless, as Dwyer and Buckle (2009) discuss, it is not the insider-outsider status that should matter "but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience" (p.59); thus, this was my aim.

During the interviews I was self-examining my interactions throughout (Hsiung, 2008). To be an effective narrative researcher, interpersonal skills are needed to listen and interpret the experiences shared (Muylaert et al., 2014); the skills I am developing as a TEP have enabled me to do this. I was conscious to follow the narrative being shared by participants as it unfolded. Therefore I was attentively listening and giving verbal and non-verbal prompts (Riessman, 2008) as well as reflecting back the spontaneous language they used to validate and encourage further elaboration (Muylaert et al., 2014). Furthermore, prior to each discussion session I completed a 10-minute meditation to enable me to fully engage in the process and be present. Following the sessions, I recorded my thoughts and feelings in a reflective diary.

3.7 Approach to Data Analysis – Narrative Oriented Inquiry

For reasons aforementioned, a NOI approach was selected for this research. This section will now discuss the steps taken following completion of the narrative interviews to analyse the narratives. Figure 2 depicts the NOI model that was followed.

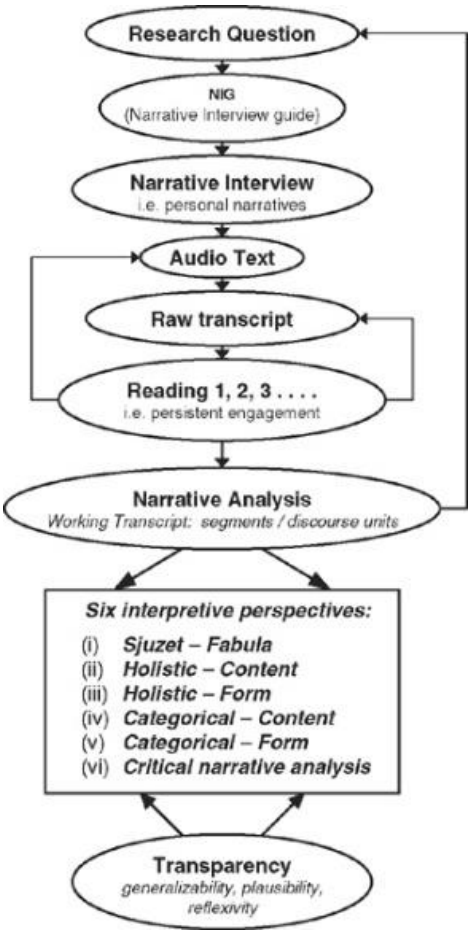


Figure 2. *Narrative Oriented Inquiry: a model.* (Hiles & Čermák, 2008)

3.7.1. Transcription and Persistent Engagement

Following discussion sessions audio files were transcribed verbatim including pauses, emphasis and non-verbals to keep the raw transcripts rich in experience as well as vocabulary (Table 1). During this process I repeatedly listened to the audios and read the raw transcripts to ensure accuracy but also for *persistent engagement,* whilst keeping reflective notes.

Table 1

Annotations Used in the Transcription Process

Annotation	Representing
,	Natural pause in speech
.	Longer natural pause of roughly one second
(2)	Longer pause, timed in terms of seconds
…	Speaker trailing off
[laughs]	Other non-verbal sounds
italics	Word emphasised by the speaker

3.7.2 Working Transcripts

Next, the working transcript was created by first separating the 'episodes' denoting shifts in telling the story. The episodes were numbered and named (Appendix O). This is a relatively transparent step that contrasts the usual convention of numbering each line as this can be considered too arbitrary, and is based in the knowledge that narratives are constructed of a sequence of episodes/events (Hiles et al., 2009). Within this step, the raw transcripts were organised into their episodes and a column was added for further notes and annotations. The further annotations that can be reviewed add to the validity of this research through demonstrating sensitivity to context, commitment and rigour, and allows for full transparency of the analysis process.

3.7.3 Fabula and Sjuzet

The next analytical stage was completing the first of six interpretative perspectives: *separating the fabula and sjuzet*. This stage is key to the NOI approach (Hiles et al., 2009, 2010) as it distinguishes the concrete events of the narrative (fabula) and the comments offering a window into the narrator's experience of them (sjuzet). The concept of fabula and sjuzet was derived from Herman and Vervaeck's (2001) 'bounded' and 'unbounded' narratives; where if the bounded, or fabula, is read independent of the unbounded, or sjuzet, it gives a 'flat' account of the narrated events. The sjuzet indicate how the story is told inclusive of rhetoric techniques such as emphasis, asides, reflections etc. which offers insight into how the narrator positions themselves concerning the retold events. I followed Hiles and Čermák's (2008) convention of underlining the sjuzet,

leaving the fabula blank and highlighting any sections that function as both fabula and sjuzet (Appendix O).

The next four stages are derived from Lieblich et al.'s (1998) narrative analysis (Hiles & Čermák, 2008). These approaches can be used in any combination deemed appropriate for the research, each offering a new perspective. Below I have grouped them under two headings, the holistic stages and the categorical stages. For my data, I completed all stages systematically and followed Hiles and Čermák's (2008) instructions.

3.7.4 Holistic Analysis

The first two interpretive stages require a holistic analysis focusing on the fabula, the account of events. The *holistic-content* and *holistic-form* analysis was completed by making comments on the transcript alongside populating participants' Life-Grids and creating their timeline of their relationship with their autism; this was useful as an overview of their whole narrative. The holistic-content analysis explores links across the narrative whilst also identifying turning points and formulating a core narrative: "a theme that is vivid, permeating the entire text, and is meaningful" (Hiles & Čermák, 2008, p.157). Next, the holistic-form analysis focuses on the narrative typology, progression and cohesion (Lieblich et al., 1998). Generally plots can be described by progression, regression or steady (Murray, 2015). These two steps allow for an appreciation of the underlying dynamics and purpose of participants' stories as a whole.

3.7.5 Categorical Analysis

The next two stages of analysis focused upon the sjuzet, how the story is told, considering what the narrator is communicating and why they chose to present it that way. The *categorical-content* analysis submits the narrative to thematic analysis following Lieblich et al.'s (1998) four steps. This step resulted in a table of themes under each research question (Appendix P). These themes allow for some comparison between participants but needs to be done in a way that keeps their narratives intact, thus allowing for context and doing justice to the whole story not merely the parts that make it up (Hiles & Čermák, 2007; Riessman, 2008). Following this, the *categorical-form* stage focuses on the formal aspects of the narrative. When completing the categorical-form analysis I deviated from using Labov and Waletzky's (1967) approach as the later version of NOI recommends (Hiles et al., 2010). This was because Labov and Waletzky's (1967) approach is useful for interpreting storied narratives with a temporal aspect to them. Although some of the narratives contained segments that this could have been applied to, the understanding created by Labov and Waletzky's (1967) approach would not have supported my analysis of the whole narrative and participants' identity. Therefore I chose to instead adopt Lieblich et al.'s, (1998)

approach, which the NOI model originally endorsed and Hiles and Čermák's (2008) instructions detail. The purpose of the rhetoric devices and extra-linguistic features that participants used were considered, such as direct speech or non-verbals and the possible intended effect on me as a listener. The categorical analysis stages added context to my understanding of participants' narratives and an appreciation of their interpretations whilst acknowledging the overall purpose of their narratives as to communicate with myself.

3.7.6 Critical Narrative Analysis

The final interpretive perspective was *critical narrative analysis* in which the overall function of participants' stories and how they position themselves within it was considered. I assigned identity positions throughout the narrative, which indicated how I have interpreted participants have made sense of their experiences (Hiles, 2007). This gave an overall impression of how participants position themselves with respect to their narrative, identity and specifically how they construct their autism. Annotations were added to the working transcript during this final stage demonstrating my sensitivity to participants' context through the identity positions assigned.

4 Presentation of Narratives and Interpretations

Chapter 4 presents the narratives and my interpretations of Maddison, Olivia, Chloe, Lauren and Emily's stories in turn. Their narratives were analysed following the NOI approach outlined in the Methodology chapter.

For each participant, an introductory paragraph precedes the narrative to provide contextual information; participants were given the chance to edit these paragraphs. Next the core theme will be presented before the narrative account, using quotations throughout. Following this, participants' chosen Dixit® cards will be shared before addressing the research questions for each participant. I will refer to the psychological theories introduced in the Literature Review where they support the understanding of what participants shared. However, not all theories are applied to all participants to avoid the risk of misrepresenting and over-interpreting the narratives; where a narrative did not reflect a theory, this was not applied.

The research questions being explored for each participant are:

1. What do adolescent autistic girls' narratives reveal about how they understand and identify with autism?
2. What are the influential experiences and relationships that adolescent autistic girls talk about that affect their identification with their diagnosis?

For the reader's clarity, the transcription annotations and some filler words have been removed from quotations.

4.1 Maddison

When we met, Maddison was a 13-year-old girl with autism in Year 9 who enjoyed listening to music and was passionate about social justice. She described herself as someone who tried to be kind, understanding, funny and interesting to be around. At weekends Maddison walked an elderly couple's dog and enjoyed spending time researching interesting topics fuelled by her curiosity of other people's experiences, such as transgender people. Maddison was diagnosed with autism at 12 years old. She lived at home with her Mum, Dad and older sister. Maddison attended a grammar school and enjoyed the Debate, Amnesty International and Politics clubs. Previously she went to a mainstream primary school.

I met Maddison once at her home. During the interview there were some interruptions from Maddison's family walking through. Although these interrupted the narrative flow, Maddison was able to continue, so these interruptions did not seem to break the narrative Maddison was sharing.

Maddison's narrative largely focused on friendships, the troubles at primary school and the more positive experiences at secondary. Overall, her narrative is one of progression centring around a core theme of *finding belonging and acceptance in school and friendships.*

4.1.1 Maddison's Narrative

At primary school, Maddison found friendships difficult: "*in Reception when everyone was…making their friend groups…for the whole of primary school, I didn't really because I didn't talk to anyone*" (Episode 19); she had been selectively mute during Nursery and Reception. She also shared that understanding friendships did not come naturally to her: "*everyone else just seemed to pick up on what to do especially like friendship groups; everyone knew how to make a new friend in the right way*" (Episode 17). Maddison had one close friend in Year 2, but they drifted apart in Year 5 which she could not explain "*I don't think there was any bad stuff between us…I don't really know but…I didn't really go with them anymore*" (Episode 21). Following this, friendships became more difficult and Maddison did not find another friendship group; instead she floated: "*I made a lot of friends that were in friendship groups but I never really had my own one, so I'd just go round and be like 'hey, can I hang out with you guys?*'" (Episode 20). Through a lack of other friends, in Year 6 Maddison made a "*friend-ish*" (Episode 23) with a new girl, but this was a controlling relationship: "*I don't think we were really friends she'd be like 'hey follow me over here and do this thing for me now' and I'd be like 'okay', cuz I didn't really have much else to do*" (Episode 15). There was also another girl in her year who was mean and thought herself better than Maddison: "*it was always like she was smarter than me and I always just assumed that she was better at everything*" (Episode 11). Although, the results of the 11+ meant that Maddison was accepted into grammar school and the other girl was not: "*it's funny really because…I'm pretty sure she was like positive that she was going to get in and I wasn't, and then it turns out I got in…and she didn't*" (Episode 11). Maddison seemed to enjoy retelling this story, although she also empathetically rationalised: "*maybe she just had a bad day when she had to take the 11+, I dunno*" (Episode 11). Consequently, Maddison went to a secondary school where she "*was the only one that got in from my year*" (Episode 10).

It was around this time when Maddison also started the autism assessment process: "*I think my Mum had been looking online or something and then she was like 'hey this might be a thing'*"

(Episode 25). Her Mum spoke to Maddison and asked if she wanted to be assessed, "*I was like 'okay yeah sure'*" (Episode 25). It took a long time for an appointment and Maddison had "*almost forgotten about it*" (Episode 26). Maddison went to the appointment with her parents when she was 12 years old.

Maddison described that the assessment sessions were "*really long* [and] *boring*" (Episode 27) and some activities "*seemed a bit random*" (Episode 27). When Maddison was given the "*verdict*" (Episode 30) that she was autistic she was not surprised. This is because of the research she conducted after her Mum had initially broached the subject, "*I was thinking possibly yeah I think so, maybe, so I wasn't really surprised*" (Episode 31). When the diagnosis was shared with Maddison's parents, her Mum cried which confused Maddison: "*I was…sad that my Mum was crying…I didn't really think it was a sad thing and then the fact that she appeared to think it was a sad thing…it was a bit confusing*" (Episode 31). Maddison herself seemed to accept her diagnosis as she considered that "*it's just kind of like there so, yeah I don't mind really*" (Episode 32).

Once in secondary school Maddison's friendships improved "*I'm lucky to have found some friends that like agree…in a lot of things*" (Episode 4). She had been with the same friendship group since Year 7 and was one of the "*original ones*" (Episode 9). Maddison had also started making other friends which she contrasted to her primary school experience: "*I'm…in quite a few different* [groups] *but in a different way to how it was in primary school where I'd just be like floating between them…it's more like I'm fully submerged in all three*" (Episodes 53/54). Overall Maddison seemed happy with her variety and closeness to friends at secondary.

Within school Maddison's autism affects her in "*some small situations*" (Episode 44) that means others may find her "*a bit weird*" (Episode 44). Positively, overall in school "*there's a lot of support for me*" (Episode 60); interventions are in place such as weekly check-ins with the SENCo and a learning passport for teachers to implement. This seems to culminate in Maddison's positivity about secondary school.

Maddison reflected that her autism gives her a different perspective towards situations. When describing what having autism means to her, she said, "*my brain's a little bit different I see things a bit differently maybe, get a different perspective on life I guess…an outside perspective*" (Episode 67) highlighting the contrast she feels from being 'normal'. 'Normal' was a word that Maddison used increasingly throughout her narrative, and usually said with some hesitation or irony indicating that she does not feel 'normal': "*I always thought that I didn't really fit in as much*"

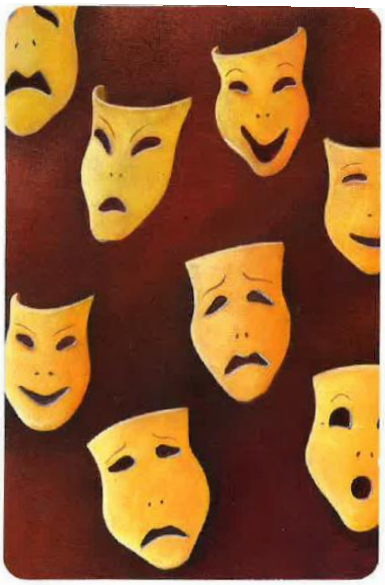
(Episode 16). She also discussed that she socially camouflages, "*you do what you think people should, how you should behave in a situation, so you got to put on a mask almost*" (Episode 69). Nevertheless, having the "*advantage*" (Episode 67) of a different perspective means that she "*can see in on* [normality] *almost, and just be like, 'hey this thing that you've always thought of as normal, I find it a bit strange'*" (Episode 67). However, she also reflected that other people may find it "*annoying*" (Episode 46).

Maddison spoke about her autism in a way that indicates she does not feel 'normal'. It has been important for her to find and connect with other autistic people to decrease potential isolation. Proactively, she went online, "*I had watched a lot of things on the internet and stuff, so I'd met-ish, I've seen other people that exist and I'm like 'okay not just me*'" (Episode 64). More recently she had a "*special moment*" with "*one of my friends who I also discovered has autism*" (Episode 52). This was a positive and important experience for her: "*it's nice that we can understand each other a little bit more…and we can like relate on a few things. It's pretty cool*" (Episode 55).

Maddison was very aware and did not want to speak for every autistic person because, "*it's so different in different people…I couldn't really speak for everyone*" (Episode 68). She also highlighted the power of stereotypes: "*what* [others] *see of autism, is not kind of what everyone with autism is like*" (Episode 68); therefore some people may have a stereotype that not every autistic person will fit, and she wanted others to understand that.

4.1.2 Maddison's Dixit® Cards

The two cards that Maddison selected are below.



Explaining this card, Maddison shared: "*this one is about how you do what you think people should, how you should behave in a situation, so you've got to put on a mask almost*" highlighting her consciousness of masking behaviours and that social expectations are important to her.

Describing this card Maddison explained: "*a normal person might read the newspaper and just read the newspaper. He might see it differently and have it projected into the night sky as stars, which I think is really pretty, but also shows that he's different*". This highlights the differences Maddison feels and the alternative perspective she has because of autism, which she frames positively.

4.1.3 How Does Maddison Understand and Identify With her Autism?

Overall, Maddison appears to have quite a positive relationship with her autism and understands it as an advantage in some ways, such as her different perspective. She described small ways in which her autism affects her day-to-day. She thought others may think some of these behaviours unusual, however her resilience to these comments developed with the support of her friends

offering her social safety and belonging, school and a positive self-concept. She also shared how her autism has impacted upon her friendships, particularly making them more difficult for her in the past. Through her narrative and the cards chosen it is apparent that Maddison is aware that she socially camouflages at times. She reflected that it was sharing this with the assessors that made their decision a diagnosis was appropriate.

The diagnosis was not a surprise for Maddison and she was ready to accept it into her identity. It is interesting to consider if her age when diagnosed (12 years) may have contributed to this, as it falls early in her identity formation years meaning she was open to exploring it. Her diagnosis seemed to name a part of her that she was already aware of as she had felt different to peers from a young age. She also seemed to consider that her autism sets her aside from being 'normal'. Maddison's narrative could be considered to indicate an 'identity achieved' status when applying Marcia's (1966) theory. She is quite committed to the autism personal identity and does not feel negatively towards it, as would be suggested by Labelling Theories (Link et al., 1989; Scheff, 1966). Maddison also has and values other identity roles such as being a social justice advocate, a deep thinker and someone with hobbies. Notably Maddison did not share that she has engaged in the Autism Community specifically beyond watching YouTube videos. Yet, she has found and aligned with an autism social identity in terms of connecting with the friend who also has autism, although the friendship was sparked regardless of this.

4.1.4 What Experiences and Relationships Affected Maddison's Identification With her Diagnosis?

Considering the relationships and experiences that Maddison shared, it seemed important that Maddison had researched autism prior to her diagnosis and therefore felt informed when diagnosed. Throughout the diagnostic process, Maddison's Mum was particularly influential. Not only did she instigate the process, she introduced the idea to Maddison and asked if she wanted to explore it, giving Maddison some agency in the situation. Furthermore, her Mum's reaction of crying when she was diagnosed was salient for Maddison who felt confused because, as she explained, she did not consider it a sad thing. Yet her Mum's reaction did not seem to have a negative effect on Maddison's identification with her autism, which may be because she felt well informed about autism prior to this. Following this, Maddison's Mum was also a figure of support, therefore perhaps superseding her initial reaction.

Friendships were a core theme throughout Maddison's narrative and demonstrated how having a sense of belonging within a peer group can positively impact an individual's self-concept. In

primary school Maddison found friendships difficult. However, in secondary school she found a sense of belonging within a friendship group who accepted her for who she is, therefore allowing her to accept herself more easily, inclusive of diagnosis. Maddison found a collective social identity through this friendship group and discussed the group's norms and values with me. Attending a grammar secondary school specifically may be significant here as it may have given Maddison greater opportunity to meet like-minded friends who will engage in the deeper conversations that she enjoys. It also seems to have supported Maddison to know and meet another autistic female so that she can feel more 'normal' and less alone.

Maddison also described an inclusive school environment where she feels well supported by the SENCo and strategies in place. However, she also reflected that it felt quite strange when her pupil passport was shared and teachers began to change their approach. Nonetheless, she since benefited from this and felt able to ask for more support if needed.

Therefore, the positive and accepting attitude of Maddison's school, friends and her Mum seem to support her to have a positive self-concept and an accepting attitude towards being a girl with autism.

4.2 Olivia

Olivia was a 12-year-old girl with autism who was diagnosed when she was 10 years old. Olivia had two dogs at home that she walked every day. She enjoyed spending time 'chilling' by spending time on her iPad, with her dogs and sitting in the garden. In the future she hoped to find a job working with animals. Olivia lived at home with her Mum, older brother and younger sister. Olivia spent time with her Dad every other weekend along with her siblings. She felt well understood and supported by her Mum, brother and staff at her school. She was highly aware of how she made other people feel and did a lot to avoid upsetting anybody. Olivia attended an autism resource provision attached to a mainstream secondary school and was in Year 7 when speaking with me. Previously she attended a mainstream primary school up until Year 5 and was home-schooled during Year 6.

Olivia met me twice in a quiet room in her resource provision. At Olivia's request, a teaching assistant (TA) was present, who was different each session. The TAs sat quietly throughout, allowing Olivia to express herself as freely as possible. It was apparent from the sessions that Olivia was a sensitive person and relives the emotions associated with a story or memory when relating it. At points when Olivia began to cry, I paused and asked her if she wanted to carry on,

as she had asked me to do. She wanted to continue and share her experiences with me, but I ensured I left time at the end for her to settle again.

Overall, Olivia's story is one of progression. Her narrative has a core theme of *needing to be noticed, understood and recognised by others.* Before her diagnosis she was unseen, unnoticed, and even dismissed. Her narrative often focused upon how well people understood her and whether she felt able to communicate her true feelings and self to them.

4.2.1 Olivia's Narrative

Socially, Olivia described herself as someone who wants friends but has trouble managing friendships: "*it was always difficult, like it wasn't that difficult to make friends but then it was keeping them*" (Episode 76). She described a general cycle that would happen:

> *We'd be friends for a bit then they would get another friend, which I was fine with but then they would not play with me as much, so I would kind of leave them alone because I was thinking that they didn't want to play with me so I didn't bug them, I don't want to be in their face. And then, we would just sort of drift apart and then we wouldn't talk at all and then I would find another person and then the same thing would happen.* (Episode 76)

Olivia was conscious of not upsetting or annoying friends and so she would not say anything, meaning it reoccurred. Olivia described having two particular friends in primary school, yet they both hated each other and that dynamic was hard to manage: "*it was too much drama with them 'Oh she said that, oh she said this, he did that' and it just got too much*" (Episode 26). Since leaving, she lost touch with them both.

For Olivia, primary school became too difficult. She found some staff unhelpful: "*I had this one teacher…she didn't really understand…she was quite old, and she would suggest things that weren't that helpful*" (Episode 12). She found the sensory environment overwhelming: "*my classroom was quite big…it's quite a crowded classroom and really loud and the lights were bright. Then the sounds…just really hurt your ears*" (Episode 35). She also found the work too hard and could not focus: "*just the work they were doing it was, it was too much*" (Episode 37), as well as finding the peer relationships difficult to navigate.

Olivia received some support and intervention at school, but found it did not suit her: "*I didn't really like it…I couldn't really express my feelings because I just felt like the person who was doing it just didn't really understand me*" (Episode 53). She also received Lego therapy which she enjoyed, but found the pressure of choosing peers each week difficult: "*In break, people would be*

like 'Can you pick me next? Can you do this?' and it just turned into I was pleasing them, but I wasn't really doing it with the people that I wanted to" (Episode 52).

Olivia seems to internalise her difficulties and feel things deeply: "*whenever anyone does something, even if they're not doing it to me, it just feels like they're doing it to me so I get quite worried and self-conscious about it*" (Episode 36). She often feels misunderstood as shy, but "*it wasn't just that I was shy, I was like really really scared but I would just put on a happy front like I wouldn't say that anything's wrong*" (Episode 65). Olivia reflected that this impacted upon her receiving a diagnosis and support: "*they were sort of comparing me to like 'Oh the boys. They're like loud and they do this, and they do that' but because girls are different…it was hard to diagnose*" (Episode 15). She was unable to share when she needed help: "*I just felt like I couldn't really say anything like if something was wrong or if I needed something…because I don't want them to say no, so I just don't say it*" (Episode 34). Olivia also described how primary school teachers had dismissed her Mum's concerns: "*they were saying like 'oh she's not the worst one in the class. She's fine' because I didn't really say anything, because I was scared and so they didn't notice*" (Episode 14). Olivia referred to this dismissal at three points in her narrative; it seemed to impact her greatly. All these difficulties led to Olivia attending school intermittently. But reintegration after a period of absence did not feel successful as she became increasingly noticed by peers, which Olivia did not like:

> *I was off for a while and then I came back and then suddenly everyone was like "Oh Olivia, are you okay, Olivia this, Olivia that" and I just didn't want all this attention and like they never paid attention to me before so I was like…"No I don't want to be friends because you never, you didn't talk to me before, you didn't notice me before"…and then suddenly when I came back they were like "Oh Olivia, are you okay? Are you this?" and I know they were doing it nicely, but then I suddenly got all this attention I just didn't want it.* (Episode 33)

Olivia did not attend school in Year 6: "*I was just finding it too hard…I don't want to go in anymore*" (Episode 38). She accessed the LA's service for young people unable to access education: "*that's when* [LA service] *came and that's when everything was a bit better*" (Episode 38). This represented a major turning point in Olivia's narrative.

Olivia's Mum began to research autism specialist schools and found the autism resource provision that Olivia now attends "*we were allowed…because I was diagnosed so I could go*" (Episode 56). At the resource provision Olivia receives specialist support and a tailored learning environment

that enables her to feel happier and able to access school ,"*I really like it because it's not, not big at all* [and] *it's away from the main school*" (Episode 39). Staff and students greet her well: "*when I come in it's like 'Hi Olivia' and I'll just go look at the timetable and sit down and that's it, it's not too much*" (Episode 42). She feels understood, and likes being with other students with autism: "*being here there's loads of other people with* [autism] *and I'm not the only one, which is nice*" (Episode 60). She has now also started to feel able to ask for help when she needs it, whereas "*before I couldn't have done that at all*" (Episode 43).

It was clear that Olivia's Mum is very important to her. Olivia looks to her Mum for her opinion, such as with teaching staff e.g. "*she was really nice and understanding, and Mum liked her too*" (Episode 51), but also in terms of herself: "*Mum says that I'm the clown at home like I'm the funny one at home*" (Episode 84). Olivia feels understood by her Mum who adapts her approach for Olivia, such as when going to bed: "*she kisses Katie* [sister] *on the head but…she just kisses her lips and blows it to me because she knows that I don't like her touching me*" (Episode 54), and "*Mum won't typically shout at me, because then she knows I'll get upset*" (Episode 22). It was Olivia's Mum, who was a nurse, that sought an autism diagnosis: "*Mum always knew that I was different*" (Episode 17), and it is Olivia's Mum that shares that information with necessary people. Olivia expressed:

> *I don't normally tell people, Mum normally, if we're meeting somewhere that it's a bit loud or they're a bit like, "oh can you please keep it…not so loud" or if they ask me a question about why I'm doing that it'll be like "oh…she has autism"…so Mum explains, I don't really say it much.* (Episode 79)

Contrastingly, Olivia's Dad did not agree and did not accept her diagnosis: "*Dad was sort of, 'oh Olivia's not this, Olivia's fine' but that was because I couldn't tell him how I felt so he didn't know…he was never there in any of the meetings*" (Episode 58). Olivia shared that whilst her Dad did not understand her diagnosis, she did not let this change her opinion of him or herself: "*because I didn't live with him, I didn't see him very often he didn't know a lot about what it, so but* [tails off], *I still like Dad*" (Episode 58).

4.2.2 Olivia's Dixit® Cards

The cards that Olivia chose are below.

Olivia explained "*all of it is in different parts and at home I'm a very different person to when I'm outside or when I'm with people that I know and trust*". This demonstrated the different personas that Olivia has in different contexts, linking to social camouflaging. For her it depends on who she is with as to how true to herself she can be.

4.2.3 How Does Olivia Understand and Identify With her Autism?

When describing this card Olivia initially resonated with the solitary character: "*I like to be alone most of the time*". She also explained "*there are words in the sky…sometimes it's difficult for me to understand what they're saying or what they mean by it*" referring to social communication difficulties and the uncertainty of interpreting others correctly.

Throughout her narrative, it was apparent that Olivia experiences communication difficulties that she attributes to her autism. She reflected upon times she has not been able to share what she was thinking or feeling due to not being comfortable, or for fear of upsetting another person; this

has led to her camouflaging. The consequences of this were that Olivia's autism was not recognised and was even actively dismissed. Olivia also mentioned differences between boys and girls with autism: she explained that girls are more likely to internalise, and boys externalise, and attributed her delayed diagnosis to this fact. Olivia described autism-associated sensory sensitivities that can disrupt her interactions with her environment such as bright lights and noise. She also described how important routine is to her and she can struggle, becoming anxious or worried, when she does not know what will happen.

Interestingly, Olivia had not heard of autism prior to her diagnosis so had no previous concept. Therefore, when she was diagnosed, she did not know how to feel about it. She now understands it as something that means she is different and needs more help. Receiving a diagnosis was validating for her and unlocked support. She communicated an understanding that there are distinct types of autism, but also recognised diversity within them. Olivia seemed to have a medicalised, deficit-based understanding of autism; she did not refer to any positive attributes.

It was apparent that Olivia greatly values her Mum's opinion and therefore her understanding of autism was initially based upon her Mum's view. Olivia seemed to have low self-esteem and did not think herself interesting, an opinion that she told me when we met. Throughout her narrative Olivia frequently compared herself to others (peers or siblings); she did not yet seem to have a clear sense of her own personal identity. Considering Marcia's (1966) theory, Olivia's identity status could be interpreted as 'identity diffused' as she has not yet explored or committed to an identity. Notably, Olivia was 12 years old when speaking with me, at the beginning of adolescence and identity formation, thus an individual of her age would not be expected to have resolved their identity crisis and developed a robust self-concept yet.

There were elements of Olivia's narrative that pertained to Social Identity Theory, such as since attending the resource provision she no longer feels like the 'only one'. This sense of belonging has been found through the similarity of having an autism diagnosis. Olivia did not refer to the wider Autism Community beyond her school.

4.2.4 What Experiences and Relationships Affected Olivia's Identification With her Diagnosis?

Olivia spoke of a few experiences and relationships that appear to have influenced how she relates to her autism. Firstly, her Mum has been highly influential in terms of instigating the diagnostic process, speaking to school staff, finding a new school and by adapting her interactions with Olivia. Olivia's Mum's influence was clear as her Mum's voice emerged in Olivia's narrative

frequently and often as direct quotations. It also seemed that Olivia's Mum shared ownership of Olivia's diagnosis as Olivia deferred to what her Mum thinks or says throughout her narrative. It is also Olivia's Mum who discloses Olivia's diagnosis to others.

Other family members have been important to Olivia too. She felt understood, supported and accepted by her brother. Olivia's relationship with her Dad was more complicated as he rejected Olivia's diagnosis and during visits, he does not adapt for her needs. This has the potential to lead to some dissonance for Olivia or tension in her relationship with her Dad. Nonetheless, Olivia shared that she still likes her Dad and that he is important to her; she does not seem to have let his opinion change her identification with her diagnosis as she highly prioritises her Mum's opinion instead and considered her Dad less informed.

Olivia's school experiences seem to have influenced her relationship with her autism. At primary school she felt different to peers but unsupported; although her school were implementing interventions, they were not person-centred. There were a few staff members Olivia liked and spoke about fondly, especially one helpful TA. However, the comments that 'she's not the worst in the class' left a lasting impression upsetting Olivia greatly, and the unsuccessful reintegration attempts meant Olivia was unable to attend throughout Year 6. Since attending the resource provision, Olivia received appropriate support and felt understood by staff. Consequently, Olivia felt more positive generally, more confident and has developed a greater understanding of how her autism affects her. She was beginning to explore her diagnosis further with the staff's support.

4.3 Chloe

Chloe was a 16-year-old girl with autism who loves BTS (K-pop band). Chloe was in Year 11 when we met, and she told me about her love of trainers, clothes and eyelash extensions. Chloe described herself as really observant and caring. When we spoke, she had recently started a new job in McDonalds working alongside her sister. Chloe lived at home with her Mum, Dad, two older sisters and two younger brothers. She had a close relationship with her family, especially one of her sisters who she frequently spoke about. Chloe was diagnosed with autism at 11 years old and attended an autism resource provision attached to a mainstream school where she was working towards her GCSEs. Previously she had attended a number of mainstream primary schools and mainstream secondary school until Year 9.

Chloe and I met once at her home. During the interview Chloe left to answer the front door, but this did not seem to interrupt her engagement.

Chloe's narrative was one of progression. A major turning point for her was being in the right provision for her needs. During Year 9 she transferred to an autism resource provision and from that point things started to change for her. Chloe's core theme was *receiving the right support to find acceptance in herself.*

4.3.1 Chloe's Narrative

Chloe had lived in lots of different places: "*we lived in* [village]…*and then I lived in* [village 2] *and then I lived here*" (Episode 9) and attended lots of different schools, which seemed quite confusing for her:

> *I went to loads of schools…so I went to* [junior school], *I went to* [primary 1]*, no I went to* [primary 2]…[primary 3], *and then I went to* [primary 1] *then I went to* [primary 2]*. And then I went to* [junior school] *and then at* [junior school] *I was there…so then I was there for* [junior school] *and I was there in Year 5 and then in Year 6 it* [assessment process] *all started.* (Episode 13)

When asked what she liked about the schools she said, "*just every school does things differently*" (Episode 20). Chloe explained that she moved from one school because:

> *I had some issues with the head-teacher, she always wanted me to come out and do extra reading with her and I was missing one of my favourite lessons…she caused so much issues that we were like "oh I'll just move"* (Episode 18)

Other schools she moved from because she moved to a new house. Chloe had both positive and negative experiences of different schools: "[junior school] *was quite good, I liked* [junior school]" (Episode 20); "[primary 2] *the classes were really big and the classes were like 30, 3 30s, so the classes were like 90 children…I liked my teachers that I had, I was only there for a year though*" (Episode 19). It was at the junior school, in Year 6, that Chloe was diagnosed with autism.

Chloe spent two years in a mainstream secondary school, which she found difficult: "*it was too much*" (Episode 21); "*I wasn't really I suppose ready to do all that…it was like moving around the school, it was all different teachers, all different students…it was the best decision to move*" (Episode 17). She did not like to go to lessons and was educated in a separate area instead, which she found limiting: "*I didn't go into any lessons…I was in this separate bit where I wasn't really doing any work, and I wanted to achieve and I wanted to do work, so I had to go somewhere where I could*" (Episode 17).

A turning point in Chloe's narrative was when she began attending an autism resource provision. She started to feel happier at school: "*we do loads of lessons that are useful, so we do like communication skills, stuff that is useful and I need help with so it's helped me quite a bit*" (Episode 22). Her home life also changed at this time when she made the decision to stop hating mess:

> *I used to* hate *mess and like obviously seven people living in a house it's going to be messy and I used to* hate *it. But now I'm just like "oh, whatever"* [laughs] *and cuz I used to be like, like a routine and…used to want to like have things a certain way but then I couldn't have it that way cuz it is just not the way life is, so I stopped being like that.* (Episode 29)

When asked when she decided to make this change she said "*oh well it was* [autism resource provision]…*when I joined*" (Episode 29).

The autism resource provision has been influential for Chloe in normalising some of her autistic traits as well as learning more about other's experiences of autism: "*I'm surrounded by people all day that have those sorts of issues so…it's really good insight to show that everyone's completely different…it's really interesting*" (Episode 33).

Nevertheless, she also shared concerns about the "*bubble*" of the resource provision:

> *If we're only in a bubble with people who are just fine with you being you, like you act in a certain way I suppose, you have to think, some things aren't appropriate and so in work you'd have to act differently to the way you do in school.* (Episode 52)

Chloe is "*really close*" (Episode 8) to all of her family, particularly an older sister: "*I get on really well with Cathie*" (Episode 8). She can ask her family for support and to explain things when she does not understand. Particularly it seems her Dad, she will "*speak to him about most things*" (Episode 30). She trusts that her family will give her the right advice and treat her fairly:

> *If I did something my Mum and Dad would tell me off so obviously* [laughs] *like if I did something that wasn't seen as right and my brothers and sisters'd get told off for it, I'd get told off for it, and they'd make me understand and explain it.* (Episode 29)

Interestingly, Chloe was not told about her diagnosis when she was diagnosed at 11. Instead she noticed letters arriving: "*I kept just seeing loads of letters that were being posted named parent or carer of me and they wouldn't let me look at them!*" (Episode 14), so she searched for them "*I went in these boxes…and then I found the letter*" (Episode 10). At this point she did not know

anything about autism, "*I didn't really think anything of it*" (Episode 10) so she "*googled it*" (Episode 11). Chloe shared that her research "*weren't really that interesting. I see a lot of it that resembled it but…it's really broad so you just had to find the specific one* [description of autism] *that matched you, so that's what I did*" (Episode 11).

Chloe discussed some of the support she received following her diagnosis: "*I went to a lot of groups I got put on with other people that were* [diagnosed with autism]" (Episode 31). However she did not connect with the others just because they were girls who shared a diagnosis: "*I got put with some girls…but at that point they all went to specialist schools…and I was still at* [mainstream secondary]*…and they were that much older than me*" (Episode 32). Nevertheless, she shared "*it was good insight to know there were other people out there…but I wasn't really interested in it*" (Episode 32).

Chloe does not mind having autism, nor does she perceive it as a barrier. She believes that she could achieve the same as non-autistic individuals:

> *I don't see myself as that different, I could achieve what everyone, like what my brothers could achieve it just might take me a lot longer. I'd might go different ways about it maybe but doesn't mean that I can't achieve it, so I don't really let it get in the way of much stuff.* (Episode 43)

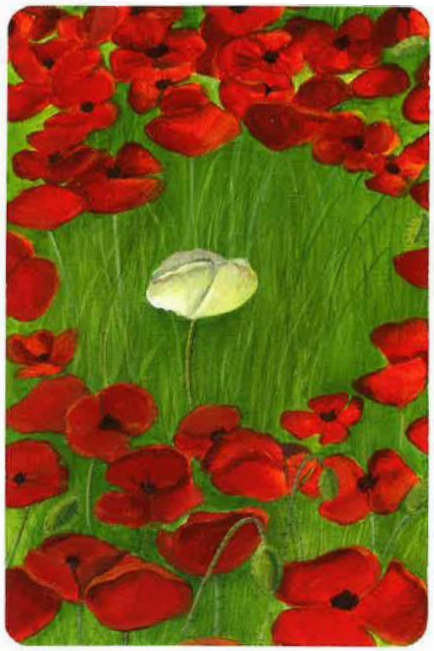
Throughout her narrative Chloe communicates the theme that 'difference isn't bad', it is just different: "*I'm just myself so I don't really care what other people think about it if like you're a bit different it doesn't really matter*" (Episode 29). At points Chloe shared her annoyance about other people's stereotypes and expectations based upon her diagnosis: "*they have the stereotype and that's what they put on you and it's just like when they say certain things and I'm and it's like 'excuse me? No'*" (Episode 41); she finds the stereotype limiting:

> [autistic girls] *are not like everyone but they just want to, to be seen as, they want to have the same goals, they want to achieve and do the things other people do. But I just don't think people think that, I think they think that they want to be on their own.* (Episode 45)

Chloe also discussed positives of her autism "*once* [individuals with autism] *learnt something we know it like with our eyes shut so all we have to do is learn it, understand it, and then that's it, we know it*" (Episode 46). She also enjoys being able to challenge people's stereotypes by not being what they are expecting of a girl with autism: "*I like to ruin their expectation*" (Episode 37).

4.3.2 Chloe's Dixit® Cards

Chloe chose two cards to explain her autism.



When describing this card Chloe said, "*there's nothing wrong with being different it doesn't mean you're bad or anything*". She explained "*the flower's still nice around the other flowers, all flowers are nice, some are different*". This seemed to highlight that although she is aware of some differences between herself and others, she embraces these and does not think it makes her any less.

When choosing this card Chloe explained:

> *Mazes are difficult but they're not impossible, it's always achievable to get to the end it just might take a lot longer…when you get to the end of something and it's been difficult it's always worth it in the end, and you think back to it and think "oh that's so easy, I could do that again"*

She also continued "*there's always going to be another* [maze], *so you just have to go through it and just keep trying*". This highlighted Chloe's resilient attitude. She recognised that she may need to learn differently to others, and it might take her longer, however that does not stop her from trying and knowing that there will be a way round.

4.3.3 How Does Chloe Understand and Identify With her Autism?

Overall, Chloe was accepting of her diagnosis and perceived it quite positively. She had no preconceived idea of autism when she discovered her diagnosis, and she had no specific emotional reaction to it at that time. Subsequently she spent time researching. Chloe does not feel like she fits the stereotypes others have of autism, and girls with autism in particular. This also seemed true in the support groups where she did not find a sense of belonging or social identity simply based upon a shared diagnosis and gender. Chloe also enjoys challenging the stereotype and educating others by "*ruining their expectations"*, rejecting their prescribed identity. This is similar to the reaction to labelling described by Modified Labelling Theory (Link et al., 1989). It seems that Chloe has a strong sense of identity to hold against others' opinions; autism does not define her although it is a part of her.

When at her current school Chloe found social belonging and acceptance as every student has autism. This meant they had shared experiences but also allowed Chloe to reflect upon the diversity of autism, which she enjoyed. She has a social category to align with at school, however she also discussed how this will change in different contexts once she is out of 'the bubble' demonstrating the contextual nature of her social identity.

Chloe held a pragmatic attitude towards her autism: she recognised positives as well as challenges, but she accepted the challenges and developed coping strategies to manage them. Autism to Chloe is a 'difference', but difference is not bad. She discussed it as a difference in the mind, with difficulties with eye contact, sympathy and empathy being key characteristics.

4.3.4 What Experiences and Relationships Affected Chloe's Identification With her Diagnosis?

In terms of important relationships, Chloe's family were very important to her. Her Dad especially featured in her narrative as a source of support. She valued that her parents have the same expectations for her as her siblings, but they differentiate explanations. Notably, Chloe did not discuss peers greatly, she mentioned that she had wanted to be alone in primary school so did not make friends. The high number of different primary schools she attended may have also contributed to this. Now in the autism resource provision she described the other students as friends.

Chloe's experiences at the many schools she attended were changeable; she has found every school different and liked them for different reasons. However, when she went to a mainstream secondary school, she found this challenging. Chloe described being educated in a separate area,

which she did not like. She also found elements of the school environment difficult, leading to her attending the autism provision. Here she found a sense of belonging and acceptance that afforded her more agency in her life overall. For example, now managing her need for routine and tidiness at home. She seemed to have developed a positive and pragmatic attitude towards her autism because of the support from the resource provision in exploring her autism.

4.4 Lauren

Lauren was 18 years old. She was very interested in books, psychology, fashion, beauty and was a qualified make-up artist. She described herself as a very sensitive person, who challenges the stereotype of girls with autism and feels that she is very much a paradox with some "*conflicting and weird*" opinions. She could also be very outgoing and confident in the right situations. Lauren was diagnosed with Asperger's at 11 years old due to experiencing high levels of anxiety and attending Child and Adolescent Mental Health Services. Lauren lived at home with her Mum and Dad; she also had an older brother and sister. Lauren attended a mainstream primary school until Year 5 and had been home schooled since, with a couple of unsuccessful attempts to reintegrate back into school. When we spoke, she was working towards achieving her A-levels and working part-time in a pub as a waitress.

Lauren and I met at her home three times. On two of the three occasions, her Mum walked through the room and contributed to the discussion. Lauren's Mum's contributions at times shaped the narrative and encouraged it to take a different turn, the implications of which were accounted for during analysis.

Lauren's narrative had an overall plot of progression before regression, as she described it: two steps forward and one step back. However, there was progression overall. The core theme was *getting to know, understand and accept herself.* As Lauren was 18 years old when speaking with me, she also focused a lot on 'growing up' and being a teenager, alongside managing and understanding her Asperger's and anxiety.

4.4.1 Lauren's Narrative

Lauren described being misunderstood by a lot of people around her: "*my family…as well as teachers and peers…some of them didn't really get it when I was diagnosed and it was like there was almost this denial*" (Episode 48). She also referred to misunderstandings specifically about autism "*because of stereotypes that people have and 'oh, well you don't look autistic'…what does it look like?!* [laughs] *It's so annoying. I just used to hear it all the time*" (Episode 20); "*another stereotype I want to break massively is people just only think of a boy*" (Episode 52). Lauren has

found the comparisons and assumptions people make based on stereotypes unhelpful: "*the normal stereotype is, 'oh autism' and then you think of bloody Dustin Hoffman and you think of a boy who is kind of very severely autistic and has meltdowns and can't cope*" (Episode 72).

Lauren experienced bullying at primary school, which she called "*emotional trauma*" and described being "punished *and* shamed *so much for being who I am*" (Episode 47). She internalised the comments, damaging her self-concept and having a lasting effect: "*there's so many things that I did when I was a kid that I was so* heavily *ridiculed for. Parents, peers, teachers that I just…carry a lot of shame*" (Episode 41). Lauren explained she had always felt different, but had not known the reason why and therefore thought she was "*defective*" (Episode 17). Lauren hit crisis point at the end of Year 5, the first turning point in her narrative. Her anxiety was overwhelming: "*I had so many panic attacks at primary school I just didn't know what they were at the time, I just knew that I didn't like the feeling and that's why I stopped going to school*" (Episode 55). She stopped attending school and received support for her anxiety: "*I've had quite a lot of different forms of therapy and all kinds of stuff over the years*" (Episode 11). The therapy for her anxiety then led to her Asperger's diagnosis: "*the whole reason I got referred in the first place was because of my anxiety issues and then* [Asperger's] *was later discovered*" (Episode 51). She did not think it would have otherwise been recognised "*I was just so good at hiding it*" (Episode 52).

Lauren spent a few years receiving therapy and learning to understand herself more: "*I never went to high school in Year 7 because I just wasn't ready, that was the same kind of time that I was getting diagnosed and starting to get help from lots of different people*" (Episode 57).

For Lauren, her anxiety and Asperger's were closely intertwined: "*I think the anxiety was just* such *a* big *part of my Asperger's as well, like it just heightened all the symptoms*" (Episode 13). However, the therapy she received helped eventually: "*having such severe anxiety I just wanted to get rid of it and I think, years and years and years and years* and years *of work kind of paid off*" (Episode 13). Once her anxiety was improving, her Asperger's also benefitted: "*I think having* [anxiety] *under control, in turn makes the Asperger's a bit more under control*" (Episode 13). Interestingly, although the therapy was successful at reducing her anxiety, Lauren found this difficult: "*no-one tells you about life after anxiety…because it had been my* identity *I guess for* so long*…I did feel a bit empty and stripped and lost of who I was*" (Episode 15).

At 11, Lauren was diagnosed with Asperger's: "*I think I knew before I got diagnosed…because of…all the sessions I was having. I overheard a lot of what they said to my parents and the kind*

of stuff that they wrote in letters…my diagnosis wasn't that shocking" (Episode 28). Nevertheless, it took some adjustment: "*when I was diagnosed…I did feel like well 'I'm a bit weird' and I didn't really understand*" (Episode 13). Her own understanding of autism at the time was based upon an autistic boy in her primary school, which left her confused:

> *My only understanding of autism before I was diagnosed was…this kid at primary school who one day…me and my friends were just stood in the hall and he was like slamming doors and he was going like this* [flapping] *and he couldn't kind of cope, it was obvious he couldn't cope and he was angry and slamming shit around…and one of my friends, he was like "what's going on, has he got anger issues or is he upset like?" and she was like "oh he's got autism I think" and I was like "oh, right okay" and so that was just my perception.* (Episode 52)

> *I literally thought it was just one singular linear kind of condition, you know, like a heart condition or cancer, I thought it was linear. I didn't realise it was such a huge spectrum of like Rhett's syndrome and, Asperger's and PDA* [Pathological Demand Avoidance] *and all that.* (Episode 53)

Lauren discussed that she thought her Asperger's had not been noticed earlier because "*as a girl…we mask very very very well*" (Episode 52). She also reflected upon her age at diagnosis: "*having autism whilst I was trying to grow up just being a normal teenager definitely made it harder and the process was slower than it was with my friends*" (Episode 9).

When reintegrating into secondary school in Year 8, Lauren used her diagnosis to explain herself to peers "*at the age of 13 I understood myself a bit better and was just trying to explain, this is why I am like this*" (Episode 37). However, this resulted in more bullying, "*I had made so much progress and it set me back again the amount of panic attacks I was having and the amount of negativity I was dealing with my peers, it just…brought it all back*" (Episode 57). She was "*ostracised*" because of her diagnosis, reinforcing her poor self-concept "*to be ostracised just for having a condition I think that's instilled…this sense of shame and like I am defective, there's something wrong with me, everyone hates me*" (Episode 68). At this second turning point, Lauren left school again and insisted on being home schooled, "*and I just never looked back*" (Episode 57).

Lauren feels everything very deeply, which she attributed to her Asperger's. She considers this a positive attribute but one that can also be overwhelming "*I just think that life with Asperger's kind*

of just heightens every emotional experience and that it is both a blessing and a curse" (Episode 56). Sometimes she wishes to not be Aspergic: "*I do sometimes wish it away*" (Episode 62) because of the difficulties she associates with it. She also may not always choose to disclose her diagnosis because "*it's almost embarrassing and shameful to talk about sometimes*" (Episode 75). But she also normalised her experiences through her understanding that everyone has problems and difficulties: "*everyone is flawed, everyone is broken, everyone has their own* crap *and I am* so *normal*" (Episode 43).

Lauren now sees herself as more in control of both her Asperger's and anxiety: "*it is just a case of having it under control*" (Episode 13) although her anxiety still occasionally surfaces. Despite attributing some struggles to her Asperger's, she also recognises that "*there are so many ways that it benefits me*" (Episode 62), such as being "*weirdly intelligent*" (Episode 51); having hypersensitivities: "*I can hear and see things better and like* smell*"* (Episode 61); learning, being "*very very receptive to information*" (Episode 61); having advanced speech development: "*I was talking pretty much in full sentences by the age of two*" (Episode 63) and having a different perspective: "*I tend to see things quite outside of the box*" (Episode 34). She also described being very empathetic as both a good thing that defines her identity as well as negative:

> *I am yeah naturally more empathetic, but also, very insecure about who I am…that is just* such *an annoying curse of having Asperger's and being so kind of sensitive to everything…but if you take away my sensitivity then you're kind of taking away the very essence of who I am.* (Episode 47)

Lauren described understanding her differences as neurobiological "*it's just a slight difference in brain wiring, I mean quite literally*" (Episode 26). She went on to explain "*we're the same species, we're just a different breed*" (Episode 76), challenging the dichotomy of 'neurotypical' and 'autistic' which she called "*too contrived*" (Episode 22). She reflected:

> [Autistic individuals'] *brain pattern and their brain wiring is similar, and therefore that's the* category *that they're in; however, it does not completely congregate them into a different sector of humanity altogether cuz we're still so much like neurotypical people if they were to give us the chance to be.* (Episode 26)

Lauren also reflected upon the differences between girls and boys and attributed the lower numbers of diagnosed females due to masking, reflecting "*it's not that it's more common in boys it's just more* obvious *in boys*" (Episode 72). Yet she explains, "*just because it's less recognised*

it doesn't mean it's not valid and that we're not struggling" (Episode 74) and that "*your perception of someone's autism is not actually how it is, that's not actually the reality of the situation*" (Episode 76).

4.4.2 Lauren's Dixit® Cards

Lauren chose four cards to represent her autism as shown below.

Lauren described "*this relates to me I think because I have a very open heart, I really wear my heart on my sleeve*". Describing the picture, she said, "*they're relating, they're vibing, they're connecting*". This seems to be connected to Lauren's view that there is a prevailing 'lack of empathy rumour' about autistic individuals, something that she rejects as she feels things deeply and finds emotional connection with others.

This picture represented Lauren's belief that "*I cultivate things that are good and bad in my life, often times I feed things that I probably shouldn't, and I feed things that I know I should*". This could relate to the paradoxical nature of Lauren that she described and the conflict that she can feel between parts of personality and the interrelation of her anxiety and Asperger's. However, she also described: "*it's a situation where you can't really have one without the other, it's both a blessing and a curse*" therefore there are both positives and negatives to be found.

This picture represents Lauren's creative side: "*I'm really into books and writing and creativity and things like that and poetry…I turn every situation I go through in life to some kind of poetry or art*". Some of this creativity she attributes to her Asperger's: "*Asperger's can be receptive to everything I go through in life, which creates for good art*". This also highlights how her Asperger's is present in every part of her life and affects how she perceives things.

The final picture that Lauren chose she described "*the bulb isn't working, you've got your own candle where it's not working…you create the light where there is none*". She likened this to herself saying "*I do have original ideas and I do try to think outside the box and I do try to shine a light on things that I can't understand*". This seems to be referring to a different perspective that her Asperger's gives her to situations and experiences.

4.4.3 How Does Lauren Understand and Identify With her Autism?

Lauren's narrative is one of herself and her Asperger's being misunderstood and judged by others, leading to her being ostracised. Lauren spoke about the interaction of her Asperger's with other elements of herself, such as her experiences of anxiety, her creativity and being a teenager.

Lauren's comment about someone's perception of another person's autism is not their reality interestingly aligns with the Critical Autism perspective described in the Introduction; the diversity in experience is something that she recognises. Lauren still seems to be exploring different identity roles and at times refers to her Asperger's as clashing with her personality, insinuating it

is separate to her personality. Yet at other points she refers to Aspergic traits that she considers to be the essence of herself. She seems to have had quite a turbulent relationship with her Asperger's, although more recently it is settling and she is becoming more accepting and understanding about how it affects her personally. She also selected identity-first language, describing herself as an Aspergic female. Nevertheless, this seems to somewhat contribute to her self-reported paradoxical nature. When Lauren was diagnosed, her diagnosis was a framework within which to understand herself, allowing her to be more accepting of herself. She understands autism as contributing both to character and ability, but not as a separate category to 'neurotypical'.

Lauren spoke about topics and shared ideas that indicated that she has engaged with the wider Autism Community. Within her narrative she referred to "*my community*" (Episode 78), demonstrating her sense of affiliation. Lauren's understanding of autism also somewhat aligned with the Neurodiversity Movement. Lauren discussed that there is not a clear dichotomy of autistic vs neurotypical. She referred to being the same species, but a different breed; echoing the neurodiversity perspective that autism is an example of natural human variation and not a distinct category.

Lauren also discussed how she does not fit the autism stereotype others may hold, which is why she may not always disclose her diagnosis. She specifically disputes the idea that individuals with autism have a lack of empathy, referring to herself as having an overwhelming amount of empathy, which in itself leads to challenges. Lauren also reflected that the reason for her diagnosis was her anxiety therapy, as she was not 'obviously' autistic due to her camouflaging abilities. Thus, without having reached a crisis point with her anxiety that required further support, her Asperger's may not have been recognised.

Considering Marcia's (1966) theory, Lauren's narrative may indicate an 'identity moratorium' status where she is still exploring different identities to commit to. Lauren was at the older end of Erikson's proposed age range for the identity formation stage (18 years) and so the theory would posit that Lauren is likely to have resolved her identity crisis. However, these are not strict age ranges and it is recognised that some individuals take longer to reach a resolution. Lauren herself reflected that she felt she had a lot to deal with in her early teens (anxiety, Asperger's, bullying trauma) along with being a teenager, additionally to being home schooled. She thought this meant some of her development was slower than her peers; thus, it is perhaps unsurprising that she does not yet seem to have an 'identity achieved' status.

4.4.4 What Experiences and Relationships Affected Lauren's Identification With her Diagnosis?

An important relationship that permeated Lauren's narrative was her relationship with her Mum. For two of the three interviews Lauren's Mum was present and contributed at points. Even when her Mum was not in the room, Lauren referred to her a lot, describing how her Mum understands her well and she relies on her support. Nevertheless, at the points where her Mum did contribute to the conversation, Lauren was often quite quickly trying to regain control of her narrative and at times disputed what her Mum shared.

Further influential relationships were friendships. The difficulties and bullying with peers at school shaped Lauren's self-concept and how she associated with her 'difference', which she later understood was Asperger's. She felt ostracised for her differences and it took much support for Lauren to begin 'rewriting' the resultant internalised negative beliefs. More recently however, Lauren described a group of friends that she seemed to be in regular contact with, she was also in her first romantic relationship. Her peer network was developing, and Lauren seemed grateful to have others to support her and now accept her, inclusive of her Asperger's.

Therapy has been hugely influential for Lauren's understanding of herself and her Asperger's. Indeed, she was only diagnosed because of her anxiety therapy. Therapy helped her improve her negative self-concept and overcome her anxiety as well as managing the transition to becoming a teenager and young adult. She started with quite a fixed and linear concept of autism based upon a boy in her primary school. However, with the support of family members and external services, Lauren's perspective changed to appreciate autism as a broad and varied spectrum that differs between males and females.

Further external influences that Lauren reflected shaped her understanding of autism include: societal norms, judgemental comments based upon stereotypes, and accessing the correct learning environment (which was home-schooling for Lauren) all in addition to simply 'growing up'.

4.5 Emily

Emily was a 14-year-old autistic girl who was in Year 9 when we spoke. Emily was particularly interested in cinematography and hoped to study this at university. She enjoyed spending time on YouTube following people that interested her, and doing role play with her school friends over a chat app. The three words she chose to describe herself were: perfectionism, self-awareness and high-quality. She lived at home with her Mum, younger brother, and dog. Emily's Dad sadly

passed away when she was 9 years old. Emily was diagnosed as autistic at 14, six months before speaking with me. The diagnosis was a result of support she received for managing her anger and anxiety. She was attending a mainstream secondary school on a reduced timetable and was in the process of gathering information for an Education Health and Care Needs Assessment referral.

Emily and I met once at her home; her Mum was in the room for most of the discussion, but only prompted Emily's memory of events three times. Emily's Mum's contribution added to the accuracy of what Emily was sharing (for example, when she could not remember names), but it did not obviously change the direction that Emily was taking the narrative.

Emily's narrative encompassed the core theme of *the importance of being noticed and accessing the right support/therapy*. Overall, her narrative is one of ups and downs: there have been times of progression and times of regression throughout.

4.5.1 Emily's Narrative

Emily described having friendship difficulties from her early years which affected her throughout primary school: "*my primary school life…was very influenced by Reception and Year 1*" (Episode 49). In Reception Emily made a friend through sharing the same birthday, however in Year 1 this friendship ended. Emily did not know what to do: "*I didn't have any friend-making skills because the only friend I'd ever made at that time was over having the same birthday*" (Episode 49). Following this, Emily was quite isolated: "*for a good two years or more…I'd spend my entire break times just alone*" (Episode 49). As a response she created some imaginary friends for herself: "*at that point I'd come up with my own solution to the problem of not having friends which was make my own friends*" (Episode 54). In Year 3 things changed for the better "*due to the fact that the teachers had actually noticed that I didn't have any friends now and so just assigned a student to being my friend*" (Episode 50). Through this buddy, "*I made friends mutually…and then, I met them, and those were the people I managed to stick with for the rest of my primary school time*" (Episode 50), but since moving onto secondary school they have "*drifted away*" (Episode 11) and lost contact.

A major turning point for Emily was towards the end of primary school when she was 9 years old: "*I did find it more difficult towards the end when my father sadly passed, erm, and from there it sort of got a little more difficult*" (Episode 12). However secondary school started more positively: "*Year 7 of secondary sort of looked up. I was back into more of a routine and so I was like more into my work again*" (Episode 13). Emily also made some friends through a long-term friend that

she knew from swimming: "*she introduced them to me*" (Episode 10). This was a good friendship group with whom she shared interests, such as role-playing games. Nevertheless, Emily was still experiencing panic attacks. During a fire drill she experienced a hallucination that her imaginary friends were giants and were attacking her and the school: "*in Year 7, early Year 8…they became the embodiment of my anxieties and my bad thoughts, and so they went from my imaginary friends to my imaginary tormentors*" (Episode 55). Then at the beginning of Year 8, she explained:

> *I'd obviously had a very difficult time with school, but I'd been not showing it outwardly so it had all been building up until like very early on in Year 8 I just had a massive panic attack before we got to school and from then on I had big trouble getting into school.* (Episode 13)

The "*massive panic attack*" (Episode 13) led to her not attending school full-time: "*we're officially on a reduced timetable*" (Episode 26). Emily was then noticed by adults and started therapy. Therapy "*calmed me down and got me through using my anger as a defence mechanism*", however she also "*felt like I'd been betrayed…they'd taken away my anger but they'd just made me sad all the time*" (Episode 31). Emily chose to end that therapy but started "*CBT* [cognitive behavioural therapy] *to find other ways of coping*" which she found helpful: "*the CBT specialist have helped me come more to terms with my emotions. So now…it isn't so much of a 'wait until she's better' because I can control* when *I'm better*" (Episode 32).

When Emily attends school she described how she finds certain aspects difficult:

> *I have quite a strong sense of justice so when I hear people misbehaving or just talking in class and then I don't see the teacher immediately running across from the child that they're helping to send them outside with a detention, then I get upset.* (Episode 20)

There are also particular classrooms that she dislikes: "*it's very textbook definition of a classroom our RE class and there's nothing different about it, and so…it makes me feel uncomfortable that's it's just like the most* usual *of classrooms*" (Episode 19).

Over the years Emily described "*I'd fluctuate in anger and trust issues*" (Episode 9) and would have "*explosions*" where "*I'd do self-destructive behaviours and then scream and fight and just generally be very not fun*" (Episode 30). It seems that Emily had been searching for an explanation to her difficulties for several years: "*I'd gone online and like obviously done the things where I just google and ask like what's wrong me*" (Episode 17). Emily spoke frequently throughout her narrative about anger, anxiety, panic attacks and depression. She found herself relating to

characters who had mental health disorders: "*I'd relate to those protagonists in those like pop culture stuff and then that would cement in my mind more that there must be something, that I have some sort of mental illness*" (Episode 37). She described wanting to know what was wrong as she "*always kind of a felt a bit different from everyone else*" (Episode 50). When she was recently diagnosed as autistic she found "*it was very clarifying for me…now I could understand what was wrong with me…so I no longer needed to ask…why I was feeling this way all the time*" (Episode 15). Emily could then understand herself and receive support: "*we've been trying to use it to help get funding for more help in school…to a varying degree of success*" (Episode 15). She was also "*put into a youth group for people of similar difficulties with general life and stuff*" (Episode 18). She then had "*a mentor*" who visited: "*it's more of just like having a friend come over who you can talk to and like get those worries off your chest whilst still having a fun time*" (Episode 18). For Emily, a mentor is better than weekly therapy, "*because over the time I've struggled to get help from a scheduled thing of a weekly therapist because it became more of a chore*" (Episode 18).

Throughout her narrative, Emily also reflected how her perspective about autism has changed. Before her diagnosis Emily had limited knowledge:

> *In one of our vertical tutor lessons we had gone through a PowerPoint I think it was on autism awareness day or something and, I wasn't exactly sure what it was, I, it didn't immediately resonate with me but…I think this is partially because of the way they were teaching it, it was more of a lesson in 'don't bully these people' and 'don't pick on them because they're different'…the lesson gave off the impression that it was quite different from other mental health illnesses because, because it seemed to be put into a whole different box whereas these were the common ones anxiety and depression, and then these are the disorders and they seemed much worse.* (Episode 35/36)

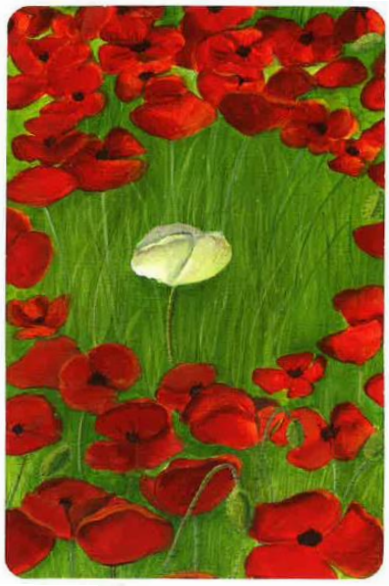
However, since conducting her own research and accessing support services, Emily's perspective has changed. She no longer "*see[s] it as a bad thing…it's more of just a way of being than it is a thing that's on top of you…it's not an illness, it's more of a personality trait*" (Episode 72). Nevertheless, Emily's autism has at times been difficult: "*it can be an obstacle*" (Episode 74). She still seems to be working out what it means to her:

> *It's just being different, but I still don't see it as something good. Like I don't think you should be bullied for it obviously, but, I wouldn't* wish *it on people or anything like that because at least* I *have had quite a big struggle with it.* (Episode 41)

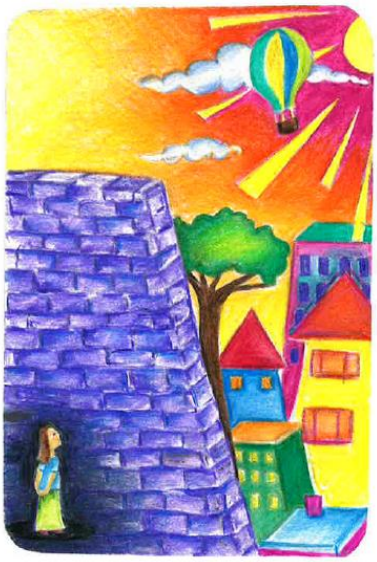
Emily also described other people's reactions "*a thing I get a lot is 'I don't know you have autism' and 'you don't seem like you have autism'*" (Episode 72). She also discussed that her group of friends have helped her: "*the biggest effect they're having is to come looking to me for help, that makes me feel like my autism isn't something that's going to hinder me, it's more of it's a part of me*" (Episode 71). Emily shared that another girl in her friendship group is also autistic and reflected that she "*experiences it quite differently from me, she finds it quite difficult as well*" (Episode 42). Nevertheless, she values this difference explaining: "*she reminds me that it's not all going to be the same*" (Episode 70).

4.5.2 Emily's Dixit® Cards

Emily chose one Dixit® card and then described an image as she could not find another to represent her thoughts. From her description an artist was commissioned to draw her second picture which was given to her during her feedback session.



When selecting this picture, Emily described that "*difference can separate you but it's also still a good thing because you're not one of the massive field of red poppies, you're the one white poppy*". She shared that she has held this attitude for a while: "*a theme in my life's narrative is that, has always been, that difference is good*". Therefore, even though her autism may make her stand out, she values this.



This card, that was created from Emily's description, was designed to represent Emily's belief that, "*whilst autism itself isn't a bad thing it's more of a personality trait, it can be an obstacle*". She went on to situate this explaining "*a lot of the time, especially in my schoolwork, I feel like I'm behind a wall that I'm not yet able to pass to be on the same level as everybody else. So, I'm stuck where I am whereas everyone else can progress*". In this sense her autism holds her back and is a barrier to her accessing and integrating successfully with everyone else.

4.5.3 How Does Emily Understand and Identify With her Autism?

Throughout her narrative Emily referred to autism in a few different guises. Her views could be interpreted as conflicting as she referred to autism as being part of her personality but also discussed considering it as a mental disorder. At points Emily also explicitly aligned herself with non-autistic teenagers demonstrating that she is still a teenager beyond her autism.

Emily seemed to be beginning to accept autism as a part of her and moving away from perceiving it negatively (a perception derived from lessons at school), but she does not conceptualise it positively either. Emily discussed the struggle that she has had being autistic. Nevertheless, as her diagnosis was recent and diagnoses tend to arise from difficulties, it is possible she has not had the time to process and consider potential positives.

Anxiety and sadness were themes towards the beginning of Emily's narrative, and she seemed to position herself as someone with anxiety and depression. Nevertheless, this became less prominent throughout; perhaps this is indicative of her evolved understanding of autism and consequently identifying herself as autistic. Emily appears quite committed to her autism diagnosis and chose identity-first language; however, she also still seems to be exploring her autism and what it means to her. For this reason, Emily's narrative could be considered to represent an 'identity moratorium' status with high exploration and low commitment, although she appeared to be beginning to commit more.

It seemed that Emily conceptualises the diagnostic label almost as currency both in terms of receiving more help and in terms of being 'special' or 'cool' (although she is consciously trying to

stay away from this opinion). The diagnosis is also valuable for Emily as a framework for understanding herself. Previously she was searching for an explanation, which she seemed to equate to a label, and was adopting ‘depression’, ‘anxiety’ and ‘anger’ to explain her difficulties. She also spoke about previously wanting a label that makes her different, which she had always perceived as a good thing. These views contradict Labelling Theories (Link et al., 1989; Scheff, 1966). Instead when she received her diagnosis, it was validating and clarifying as Pasman (2011) discusses, but beyond that it also, to some extent, made her feel special.

4.5.4 What Experiences and Relationships Affected Emily’s Identification With her Diagnosis?

Emily shared that her friendship experiences in primary school were very influential: she had some friends but not consistently as she was unsure how to make friends. This led to trust and anger issues, and the creation of her imaginary friends. Once in secondary school Emily found a friendship group, within which she found a sense of belonging. This friendship group offers her a collective social identity as a group member even when she is not attending school fulltime. Emily discussed how she has shared her diagnosis with her friends and that she appreciates that they have accepted it and continued to act the same towards her. She also spoke about her autistic friend who influences her perspective on autism, reminding Emily not to assume that everyone is the same.

The fire drill in Year 8 was a significant experience for Emily as it highlighted her difficulties to others, which resulted in her receiving support; and subsequently her diagnosis. Receiving a diagnosis was particularly influential because it changed her perspective about autism. Before her diagnosis, Emily’s understanding of autism was from a lesson, from which she understood autism as a mental disorder and something to not bully people for. She found minimal aspects that resonated with her own experiences. Following diagnosis, Emily and her Mum conducted their own research and the information they found, such as the NHS dimensions tool, has helped her understand autism in a wider sense.

Therapy has also been important for Emily. Interestingly, the therapy that Emily received that helped her anger, she felt betrayed by. She discussed having been left vulnerable and sad without her defence mechanisms. Instead the CBT she started, she found more supportive and felt optimistic about the possibilities of having more agency in ‘getting better’. However, Emily also reflected that a therapist had discouraged her from exploring an autism diagnosis. Emily wondered if the therapist thought she would just label herself with it, as she had been searching

for a label that fit. Despite this therapist's opinion Emily and her Mum began the diagnostic process.

Emily also spoke about some significant staff members. She mentioned her Year 3 teacher who was the first to notice her and positively impacted her primary school experience by organising a buddy. In secondary school, Emily mentioned her SENCo as a significant person, however this was a more negative influence as Emily did not feel supported despite the school implementing strategies.

Another significant person to Emily was her Mum who she had a very close relationship with. It was apparent that Emily's Mum was a positive person, accepting of Emily through her ups and downs and knew her well. Emily's Mum initiated the diagnostic process because she wanted to explore all the options to understand how to help Emily. Emily considered home a safe place where she could relax fully and be accepted for her true self.

5 Discussion

This chapter begins by considering what participants' narratives collectively indicate in relation to the research questions, incorporating findings from existing research and theory. The arising implications will also be shared. This research will then be evaluated for quality, strengths and limitations before considering future directions for this topic. A reflexive account is included, and conclusions discussed. Finally, to complete this dissertation, participants' messages about what they wanted others to understand about autistic girls will be presented.

5.1 Research Question 1: What do Adolescent Autistic Girls' Narratives Reveal About how They Understand and Identify With Autism?

As already highlighted, each participant has a unique background that impacts how they make sense of their autism diagnosis. It is important to recognise the systemic influences upon individuals' experiences and understanding of autism, such as their peers, family, community and wider political contexts. Thus, participants' accounts are heterogeneous and ideographic. This has specific implications for EPs working within these systems (as will be explored in section 5.3.2). In this research, each individual differed in their exploration of and commitment to their diagnosis, leading to different identity statuses being interpreted and different personal constructions of autism. Below I will discuss some similarities and inconsistencies between the narratives, illustrating how these adolescent autistic girls communicated their understanding of and identification with their autism. This discussion will begin by considering what the participants shared as understanding were their autistic traits before exploring how they interpreted and understood these within their identity.

5.1.1 Autistic Traits

Participants discussed the impact of their autism throughout their lives; all described ways in which it affected them at home, school and in relationships, showing it impacts upon multiple areas of their lives. All participants described traits they recognised within themselves as autistic, although these differed between participants. Some traits that were identified as challenging were: communication difficulties; lack of eye contact; need for routine, similarity, and predictability; needing more help; sensory differences; and a lack of empathy and sympathy. These traits are recognised in existing literature and are characteristics acknowledged in the diagnostic criteria (American Psychiatric Association, 2015; World Health Organisation, 2018). Yet, participants also deviated from the deficit-focused discourse by describing positive traits they attributed to their autism, including: finding it easy to learn; having a unique and different perspective; good

memory; improved empathy; early language development; advanced intelligence; being very observant and creative. These positives closely align with those discussed in the Literature Review. Interestingly, improved empathy specifically challenges the common autism discourse. Some researchers are finding that autistic females may have better empathy skills than autistic males (Hadjikhani, 2014; Sucksmith et al., 2013) thus there may be a need to challenge this stereotype. All participants also expressed that autism is a diagnosis with much diversity between individuals meaning that one description of autism is not sufficient for everyone. This resonates with Treweek and colleagues' (2019) recognition of the importance of the heterogeneous nature of autistic individuals.

Notably, Olivia and Emily did not describe positive traits that they directly attributed to their autism as others did, reflecting Milner et al.'s (2019) single participant who did not discuss positives. Olivia particularly seemed to communicate about autism mainly through a medical model framework, which may have been influenced by her Mum's profession as a nurse. This highlights how influential a parents' understanding of autism can be to how an individual understands and manages their autism (Beteta, 2009; Logsden, 2010; Theara & Abbott, 2015). The family's cultural beliefs about disability vs. neurodiversity will impact upon the girls' construction of her diagnosis as that is how it will be spoken about and managed at home (Therea & Abbott, 2015). Parental views will also impact if a diagnosis is sought.

All participants, including Olivia, also communicated an understanding of autism as a difference as opposed to disability aligning with participants in Feist's (2013) and Brownlow's (2010) research. Additionally, three participants explicitly spoke about difference not being bad, highlighting the positive attitude they held, aligning with the Neurodiversity Movement (Jaarsma & Welin, 2012). However, how much each participant committed to the perspective of being 'different' and how much emphasis they afforded it in their narrative varied. Interpreting autism as a difference and not disability is likely to be a protective factor for their psychological wellbeing and self-esteem (Brownlow, 2010; Feist, 2013).

5.1.2 Friendships

Maddison, Olivia, Chloe, Lauren and Emily all shared challenging experiences with friendships that they attributed to their autism, similarly to the literature (Cook et al., 2018; Cridland et al., 2014; Kirkovski et al., 2013; Myles et al., 2019; Sedgewick et al., 2019; Tierney et al., 2016; Vine Foggo & Webster, 2017). Emily and Olivia shared an uncertainty about initiating friendships. In contrast, Maddison and Lauren shared that they could make friends, however *maintaining*

friendships was difficult. Interestingly, Maddison explicitly contrasted herself to her non-autistic peers reflecting that she did not intuitively know how to manage friendships as she did not instinctively learn the implicit social rules, as other research suggests (Edwards, 2012; Logsden, 2010; Moyse & Porter, 2015). Moreover, Chloe and Olivia shared that they can prefer to be alone sometimes, aligning with participants in Vine Foggo and Webster's (2017) research.

5.1.3 Camouflaging and Internalising

Four of the five participants discussed camouflaging and the impact upon themselves or their access to support. They all explicitly linked camouflaging to being autistic. Camouflaging is a significant topic in the autistic female literature as was highlighted in the Literature Review. As Cage and Troxell-Whitman (2019) suggest, autistic girls may camouflage due to societal pressures of being a minority within a minority and feeling unable to 'fit' either the 'female' or 'autistic' stereotype. It is unsurprising then that participants discussed camouflaging and were consciously aware of it. However, it is also important to recognise that it is societal pressures to conform that leads to camouflaging, and potentially the negative consequences. Thus, with more inclusive environments camouflaging is less needed (Cook et al., 2018) which leads to some significant implications, as will be discussed in Section 5.3.2.

However, camouflaging was not described by all participants, as previous research also reflects (Hull et al., 2020; Milner et al., 2019). Interestingly Chloe did not describe camouflaging; instead saying "*I like to ruin their expectation*", insinuating that she may not feel the pressure to conform to society generally, or society's expectation of an autistic girl. This highlights the heterogeneity of participants' experiences. It cannot be assumed that every autistic female will camouflage despite this becoming a key characteristic in the autistic female discourse (Hull et al., 2020; Milner et al., 2019).

Related to camouflaging, an aspect of Olivia, Emily and Lauren's understanding of autism was that autistic girls internalise difficulties, reflecting the literature (Bargiela et al., 2016; Cook et al., 2018; Mandy et al., 2012; Moyse & Porter, 2015). Olivia articulated this clearly when sharing that people thought she was shy, when instead she was "*really really scared*". It was this 'double empathy problem' (lack of bi-directional insight between autistic and non-autistc individuals; Milton, 2012) that led to her teacher dismissing her, not receiving the right support and ultimately left her unable to attend school. Emily also described internalising difficulties. Similarly to Molloy and Vasil's (2004) participant, in response to not having friends, Emily created imaginary friends who "*became the embodiment of my anxieties and my bad thoughts*" and grew to become her

"*imaginary tormentors*". Yet, as this was coupled with camouflaging behaviours, others were unaware of her struggle and thus only supported her following her major panic attack at school; providing further evidence that autistic girls may not be noticed until reaching crisis point (Zener, 2019). Lauren articulated the notion of girls specifically internalising difficulties well: "*it's not that* [autism's] *more common in boys it's just more obvious in boys*". The in-depth and personal understanding participants expressed of both camouflaging and internalising difficulties relates directly to the research and highlights that adolescents are also acutely aware of the phenomena.

5.1.4 Autism as an 'Obstacle'

Both Lauren and Emily described their autism as an 'obstacle' in their narratives and as contributing to a sense of feeling 'different', a theme found elsewhere in the autistic female literature (Feist, 2013; Kanfiszer et al., 2017; Leedham et al., 2020; Milner et al., 2019; Zener, 2019). Emily articulated this 'obstacle' particularly clearly when describing an image for her custom card. The notion of autism as an obstacle has previously been found for autistic females relating to friendships, school, employment and romantic relationships (Cook et al., 2018; Haney & Cullen, 2017; Kock et al., 2019; Myles et al., 2019; Tierney et al., 2016). Lauren also indicated that in the past she found her Asperger's an 'obstacle' but has since shifted her perspective and is now conscious to not *let* it be. This highlights the dynamic nature of individual's constructions of their diagnosis and how their perspective and identification with it can change by assimilating new experiences and knowledge (Kock et al., 2019). Chloe also shared that she does not let her autism be an obstacle discussing that autism may change her approach however with adjustments and time, she will achieve anything she wants to. This seems to indicate that Chloe believes that she can find coping strategies to manage challenges that she associates with having autism.

As Mogensen and Mason (2015) note, the extent of agency and control that individuals may gain as a result of having a diagnosis is important in defining whether they interpret the diagnosis as an advantage or disadvantage. If aware of their autism and its related traits (the positives and challenges), individuals are perhaps more able to develop suitable, individualised coping strategies (Sanderson, 2000). Consequently, helping them to overcome the sense that autism may be an obstacle. This is supported by participants' narratives, with Emily, Olivia and Lauren all reflecting upon the importance of developing self-awareness.

5.1.5 Accessing Support

All participants referred to ways in which having a clinical diagnosis benefitted them through subsequent specialised support; a recognised positive of labelling (Pasman, 2011). For example, Olivia and Chloe attended specialist resource provisions; Maddison received extra support within her grammar school; and Lauren received more targeted and bespoke support through LA services. These participants also add conviction to the argument that autistic girls may need support in the absence of academic need (Baldwin & Costley, 2016; Jarman & Rayner, 2015; Moyse & Porter, 2015; Such, 2017; Tomlinson, 2019). Yet not all support offered was helpful. Olivia did not benefit from some of her mainstream school interventions; she explained that she could not express herself because she did not know the adult and was not comfortable in the group context. Olivia's experience aligns with much of the literature that highlights there is a lack of *appropriate* support for autistic girls (Jarman & Rayner, 2015; Milner et al., 2019; Mogensen & Mason, 2015).

It is also pertinent that both Emily and Lauren were receiving therapy for mental health reasons prior to their autism diagnosis. It was that therapy that led to investigating autism. As previous literature highlights, mental health difficulties are often co-morbid for autistic females (Baldwin & Costley, 2016; Lai & Baron-Cohen, 2015; Rynkiewicz et al., 2019). Lauren specifically highlighted the interactive nature of her Asperger's and anxiety throughout her narrative. Thus, any support received needs to be responsive to all of the needs of the young person, not only their autism.

5.1.6 Identification With the Autism Community

Although all participants spoke about knowing others with autism from school, only Lauren discussed engaging with and socially identifying with the Autism Community. Research by Cooper and colleagues (2017) would suggest not developing an autism social identity could leave individuals more susceptible to anxiety, depression and low self-esteem. Cooper et al. concluded that this effect is mediated through personal and collective self-esteem, as would be supported by Social Identity Theory. Therefore, it seems that the current participants were developing an autism social identity elsewhere, such as through meeting other autistic individuals in person as opposed to necessarily engaging with the Autism Community online.

5.1.7 Sense-Making Process

For the majority of participants, receiving a diagnosis allowed them to construct a new sense of themselves, as previous research participants found (Baldwin & Costley, 2016; Feist, 2013; Haney & Cullen, 2017; Kanfiszer et al., 2017; Kock et al., 2019; Leedham et al., 2020).

Participants' narratives made it apparent they were negotiating and exploring their own autism by researching and finding descriptions that resonated with them. All but Olivia described having engaged in some active researching during or following diagnosis. Researching autism and reading accounts of others' experiences influences an individual's sense-making process (Feist, 2013; Leedham et al., 2020; Logsden, 2010; A. Webster & Garvis, 2017). Logsden (2010) specifically concluded that the more intervention and books read, the more accepting and aware her participants were of their Asperger's. Thus, it is reasonable to assert that participants' research informed their sense-making and identity exploration.

Interestingly, Chloe did not describe finding a new sense of herself following diagnosis and instead described feeling quite unchanged. This has also been reported by others in the literature (e.g. Samra, 2016). Diagnosis itself is not always a significant turning point and important to identity (Macleod et al., 2013) as instead what matters is the meaning an individual attributes to it. For Chloe, her narrative's major turning point was attending her autism provision with specialised support and consequently, she started understanding herself more. It is apparent that all participants needed the right support and environment to develop self-understanding and explore their diagnosis. Their sense-making processes began at different points, dependent on their accessible resources, support and self-awareness.

Overall, all participants seem to accept their autism diagnosis, none rejected it as others have in previous literature (Logsden, 2010). The majority have been active in exploring and constructing their autism understanding, for example through researching, when they are in the right environment with the right support. All participants communicated an understanding of autism as a difference and not a disability, which seems to counteract the potential negative effects of labelling as described by Link et al. (1989) and Scheff (1966). Yet, importantly, not all considered autism as advantageous. Although these participants may have had some similar experiences, their narratives and the interpretation demonstrate how complex and multi-faceted their understanding of and relationship with their autism is.

5.2 Research Question 2: What are the Influential Experiences and Relationships That Adolescent Autistic Girls Talk About That Affect Their Identification With Their Diagnosis?

Below I will discuss similarities and discrepancies of hindering and supportive relationships and experiences as reflected through participants' narratives.

5.2.1 Hindering Factors

There were many experiences (internal and external) and relationships that seemed to hinder participants' identification with their autism by making their exploration of their autism more difficult, or association with autism more negative.

5.2.1.1 Internal Experiences. Three out of the five participants spoke about their experiences with mental health difficulties. Adolescent autistic girls seem to be particularly at risk of mental health difficulties (Zener, 2019), and the current participants' experiences support this. Lauren, Olivia and Emily spoke about their experiences of anxiety, anger and depression. Lauren and Emily specifically discussed their panic attacks and their associated feelings of confusion and fear. Trembath et al.'s (2012) research showed that a common consequence for autistic individuals experiencing panic attacks is to become less exploratory in behaviours for fear of triggering another attack, thus hindering opportunities for exploring identity roles. This has the potential to be particularly limiting within the key years for identity formation (Erikson, 1968). Additionally, as Lauren shared, frequent panic attacks and overwhelming anxiety can become a personal identity. Thus, when an alternative may become available, such as autism, it may be more difficult to explore this, as was also seen in Molloy and Vasil's (2004) participant.

Another salient internal experience was Maddison's selective mutism during Nursery and Reception. Selective mutism, when an individual is unable to speak in specific social situations, is often comorbid with autism (Steffenburg et al., 2018). It is currently understood through an anxiety framework (Steffenburg et al., 2018). Thus, although Maddison did not explicitly express feelings of anxiety as other participants did, it is likely that she was affected by anxiety to some extent, which directly impacted upon her friendships.

A final internal experience participants discussed was feeling different to peers and being misunderstood by others. Feeling different and misunderstood can lead to isolation, as all participants expressed at points in their narratives, which can then limit opportunities for identity exploration, or limit motivation and confidence to do so (Mogensen & Mason, 2015). Lauren's primary school experience illustrates this. Nonetheless, feeling different was not always positioned negatively, as will be explored in Section 5.2.2.3.

5.2.1.2 Relationships. All participants discussed significant difficulties with relationships that meant they were more likely to frame autism negatively and as a disability. Friends were very influential for all participants, albeit Chloe to a lesser extent. Olivia, Emily, Maddison and Lauren all described negative friendship experiences. Friendships are recognised as a main area of

difficulty for autistic girls (Kirkovski et al., 2013), this is particularly important as friendships are also pivotal for identity development (Pasupathi & Hoyt, 2009). Therefore, the lack of secure friendships in primary school described by Emily and Maddison, the difficulty managing friendships described by Olivia, and Lauren's bullying or "*emotional trauma*", are all detrimental to developing a positive self-concept and identity. Previous literature suggests that the influence of negative peer relationships can be negated by protective factors such as a strong sense-of-self (Edwards, 2012; Gaffney, 2017). It seems from participants' narratives they did not have a strong sense-of-self during their primary school years. The bullying described by Lauren significantly impacted her identification with her diagnosis as the bullies specifically targeted her Asperger's. When bullied for a specific trait or part of yourself, it is then harder to like that aspect and accept it as part of your identity (Boulton, 2013; Van Hoof et al., 2008). Furthermore, Greenlee et al. (2020) found a link between bullying and poor mental health in autistic girls, demonstrating the highly negative impacts of bullying for this population. The importance of friendships also arose as a core theme throughout Maddison's narrative. For her it seemed that her psychological wellbeing was closely linked to her feelings of friendship. Nevertheless, despite the difficulties some participants faced, they also experienced positive friendships as Section 5.2.2.1 will explore.

Notably friendships were not as prominent for Chloe as they were for other participants. Chloe described that when she had attended mainstream schools, she preferred to be alone and was not motivated to have friends. Chloe's motivation seemed to increase once attending the autism provision. It is possible that Chloe's fragmented primary school experience may have made developing friendships particularly difficult. Additionally, she may feel more attuned to the students at the autism provision having found a joint social identity. Alternatively, perhaps the mainstream environment contained other difficulties for her to overcome and therefore friendships were too much to manage at that time. Nevertheless, the hypothesis also needs to be considered that Chloe's social motivation may have changed as she matured. However, the underlying reason for Chloe's friendships was not found in her narrative.

Further relationships that were discussed as negatively affecting participants' experiences of autism were with school staff. It is unfortunate that sometimes staff do not have the knowledge or awareness to support autistic girls effectively (Jarman & Rayner, 2015), as was the case for some participants. Olivia's narrative of being dismissed by a teacher was particularly salient. Although her mother was expressing concerns and asking for support, because Olivia was "*not the worst in the class*", she was overlooked, similarly to other parents in existing literature (Cridland et al.,

2014). Importantly, Olivia reflected that she was not externally expressing her struggles which may have contributed to the teacher's interpretation. Instead, she was internalising her difficulties which consequently left her feeling unable to attend school. The experience of being dismissed and disbelieved by school staff has also been reported elsewhere (Gaffney, 2017; Jarman & Rayner, 2015).

Being rejected by a professional can be very influential. For example, Gaffney's (2017) participant reflected that when her teacher questioned her diagnosis, it left her feeling confused and questioning the diagnosis herself. Furthermore, in this research, Emily described her therapist discouraged her to explore an autism diagnosis which made her question if she should. The adult autism literature shows that when others reject the diagnosis, the individual experiences higher rates of stress, depression and camouflaging (Cage et al., 2018). This likely compounds the camouflaging that is already highly prevalent within populations of autistic females.

5.2.1.3 External Experiences. Further experiences of note include Lauren and Emily's reflections upon therapy. Although both had some positive experiences, Lauren and Emily mentioned feeling betrayed and let down by therapy. From an external perspective, this therapy may have appeared successful as it removed their anxiety and anger. However, both described that they were left feeling vulnerable as anxiety and anger had been a major part of who they were; Lauren had explicitly identified as an 'anxious person'. Thus, it is important to recognise individual experience during therapy and ensure it is appropriate.

Additionally, Olivia and Chloe discussed some interventions and school support that were ultimately negative experiences. For Olivia, some of the therapeutic interventions she received in primary school did not support her due to the group context and her unfamiliarity with the adult. This highlights the need for support and intervention to be person-centered and to ensure the context suits the individual (Sanderson, 2000). Similarly, Chloe described a social group with other autistic girls as unhelpful. Although Chloe valued knowing she was not alone in her experiences, the other girls were different ages and went to different types of school. This meant that Chloe did not develop a sense of belonging, as is often the aim of social groups of this type (Baker, 2007).

Some participants also reflected upon their limited knowledge of autism before their diagnosis which led to confusion when they were diagnosed. As Labelling Theory would suggest, an individual's knowledge of a label prior to being diagnosed is important for how they come to understand the label (Scheff, 1966). Emily explained her knowledge of autism came from a lesson

where she described the focus of the lesson as ‘don’t bully these people’. It is known that autistic individuals are more prone to being bullied (Sterzing et al., 2012), and this lesson may have been the school’s attempt to address this. Crucially, for Emily, the lesson singled out autistic individuals as having a mental disorder and left her ill-equipped to understand what autism was. Lauren also reflected that her understanding of autism before diagnosis was linear and fixed. She described watching an autistic boy in primary school having a ‘meltdown’ which shaped her understanding; specifically, she thought that autism only affected males. However since her diagnosis she has broadened her understanding from reading, receiving support and meeting others, as is common following a diagnosis (Leedham et al., 2020; A. Webster & Garvis, 2017). Despite unhelpful starting points, participants were able to assimilate new knowledge and change their original constructs of autism, highlighting the dynamic nature of an individual’s understanding and identification with their diagnosis.

5.2.2 Supporting Factors

Although there were many relationships and experiences that hindered, there were also relationships and experiences that supported participants’ identification with their diagnosis.

5.2.2.1 Relationships. Supportive relationships were a major influence upon each participant. All participants described the support and understanding of their Mum. This has also been seen in other literature (Beteta, 2009; Cridland et al., 2014; Tierney et al., 2016). Additionally, Chloe mentioned the role of other immediate family members: her Dad for example was very influential and supportive. Chloe also had a very close relationship with her sister, with whom she shared many interests. Olivia also mentioned her older brother as being supportive and understanding of her.

Beyond family, participants described friendships that were influential, a finding reflected in existing literature (Feist, 2013; Gaffney, 2017; Logsden, 2010). It was important for both family and friends to be supportive and accepting of the individual to develop their positive self-concept and identity. Emily described the importance of her friends treating her the same following her diagnosis, which made her feel that “*autism isn’t something that’s going to hinder me, it’s more of, it’s a part of me*”. This encourages her to conceptualise autism as a difference, not a disability, aligning with the Neurodiversity Movement.

Further relationships that have been important are those of teaching staff. Participants described specific staff members that were helpful, such as Emily’s Year 3 teacher. Prior to Year 3 Emily did not have friends at school. This teacher noticed and organised a buddy for her. Many schools

have buddy systems in place that can be supportive for autistic individuals (Laghi et al., 2018). However, first the individual needs to be identified as needing support, which can be especially challenging if the individual camouflages. This highlights the importance of Emily's teacher firstly noticing her. Olivia also described a TA that she found helpful: "*she was really nice and understanding*". Olivia's TA ran her Lego therapy sessions which she thought improved her communication, despite difficulties in choosing accompanying peers. The way in which Emily and Olivia described these teachers reflected Jarman and Rayner's (2015) finding that taking a personal approach, being adaptable, and students feeling liked were important values in teaching staff when supporting autistic girls.

The last supportive relationship to discuss is having an autistic female friend. It is important to meet other autistic individuals to be able to engage in an 'autism identity' (Macleod et al., 2013). It may also support individuals in their social comparisons to have someone with the same diagnostic label as them which may normalise some of their experiences. All participants mentioned other autistic girls they have met. Both Emily and Maddison specifically discussed having a close autistic female friend who they found particularly supportive. Maddison described their mutual disclosure as being a "*special moment*". Importantly for Emily, the differences between herself and her autistic friend reminds her of autism's diversity. By having the same diagnosis but meeting through means other than a support group, seems to have helped both Maddison and Emily feel more comfortable about their autism at school and feel less alone.

5.2.2.2 External Experiences. As aforementioned Lauren and Emily had some negative experiences with therapy, however therapy was also supportive in their sense-making process and identity exploration. Therapy can be supportive in this way for many individuals if the type of therapy is appropriate. Emily for example spoke about CBT that is now helping her to develop more adaptive coping strategies.

For both Lauren and Olivia, being homeschooled and accessing LA support services was a positive turning point in their narratives. Olivia reflected "*that's when everything was a bit better*". For both, home schooling was a positive option at the point that attending school had become overwhelming. Home schooling has been increasing in popularity for autistic individuals (Simmons & Campbell, 2019). Fulltime home schooling or 'flexi-schooling' where education is shared between home and school, are sometimes considered preferable to fulltime school education (Lawrence, 2018). Notably Lauren and Olivia subsequently accessed different secondary education, where Lauren remained being homeschooled and Olivia attended an

autism provision. For both, it seemed important that home schooling marked the end of their negative experiences of primary school, thus it was supportive and enabled them to cope better with their challenges.

Having the right school environment is also important. Maddison, Chloe and Olivia all described schools they attended that took an individualised approach to support, as recommended by Jarman and Rayner (2015). For Maddison, this included having a pupil passport and weekly SENCo check-ins - strategies that are suggested for supporting autistic girls in mainstream schools (McCann, 2019). Chloe and Olivia described the support that they received at their autism resource provisions, which included visual timetables, communication skills lessons and understanding staff. It was apparent that both Chloe and Olivia felt more understood in their resource provisions than they had in mainstream schools even with the adaptations implemented. Research has shown that autism resource provision parents and pupils often perceive academic and social benefits from attending resource provisions over mainstream schools (Hebron & Bond, 2017).

Further experiences that appear to have positively influenced participants' identification with their autism is the opportunity for exploring interests. Maddison for example spoke about doing trapeze and walking dogs; Lauren spoke about her make-up artist qualification, and interest in literature; Emily spoke about her interest in cinematography and role-playing games. It seemed important for participants to explore other interests and identity roles to understand if and how their autism integrates with these. It also helps them to develop a sense-of-self that can build upon strengths and interests beyond their autism diagnosis, as was identified as necessary by Molloy and Vasil (2004).

5.2.2.3 Internal Experiences. The key to understanding the influence of the experiences described above is in understanding how participants have interpreted them and the resulting internal experiences. Olivia explicitly spoke about feeling understood by others and the importance of this to her, reflected in her core theme. From analysis, this was important for all participants' influential relationships. Feeling understood validates an individual and enables them to accept themselves more easily. Subsequently, they are then more likely to integrate that aspect of their personality into their identity (Cage et al., 2018).

As aforementioned and found in previous literature (Mogensen & Mason, 2015), for some participants, the feeling of being different was not always negative. Emily, Chloe and Maddison spoke about valuing difference, or difference not being bad. This positive attitude to difference

means that they are more likely to accept and identify with a label that suggests they deviate from 'normal' (Feist, 2013; Vella Gera, 2017). Thus holding, or retrospectively developing, the opinion that difference is positive supports individuals to conceptualise their diagnosis as a difference not disability, as endorsed by the Neurodiversity Movement, and as is beneficial for wellbeing and identity (Carrington & Graham, 2001; Cooper et al., 2017; Feist, 2013).

A sense of agency, which can be defined as the control an individual has over their own actions and the influence they have in the outside world (Haggard & Chambon, 2012), has also been important to some participants. Having a sense of agency or control is positively linked with self-efficacy and resilience (Rutter, 2013). This is even more important during adolescence when individuals are developing independence from their care givers (Szwedo & Hessel, 2017). Certain experiences in participants' narratives supported their sense of agency, such as starting jobs (as described by Chloe and Lauren), or Maddison's involvement in instigating her diagnosis process. These types of experiences increase their independence and agency, which in turn positively affects identity development. This is because individuals can apply this sense of independence to a more personal exploration of their diagnosis.

Finally, an important theme in all participants' narratives was their sense of belonging. This reflected Logsden's (2010) findings that belonging is vital to a positive sense-of-self and identification with their diagnosis. To have a sense of belonging is a human psychological need (Maslow, 1943), and has been found to be a protective factor for positive psychological wellbeing (Baumeister & Leary, 1995). This has also been found within cohorts of autistic girls (Myles et al., 2019) who, as a population, are at increased risk of poor psychological wellbeing (Rynkiewicz et al., 2019). Participants described both a lack of belonging (when feeling different and isolated) and a positive sense of belonging in various guises. Chloe seemed to feel a strong sense of belonging and emotional connection with her family, which was a protective factor for her throughout her school moves. Olivia had contrasting experiences between each of her parents. Yet, Olivia so strongly felt understood and accepted by her Mum this acted as a protective factor against her Dad's denial of her diagnosis. Emily reflected upon her sense of belonging within her friendship group and the advantage that her diagnosis did not change this. Lauren found her sense of belonging within her family and in her group of friends. Maddison reflected on her sense of belonging within her friendship group at secondary school and directly contrasted it to primary school. All participants had some clear positive consequences from their sense of belonging and it seemed supportive for their wellbeing and identification with their autism when they were accepted and liked by others.

5.3 Implications

This section will first consider some general implications of this research before considering specific implications for EPs.

5.3.1 General Implications

5.3.1.1 Rethinking Assumptions. An important message that emerged from participants' narratives is the importance of challenging assumptions. All participants reflected upon how other people's unhelpful stereotypes affected them. They all described this with a sense annoyance about having to explain or prove the other person wrong. The assumptions around their diagnosis were a barrier they had to break through before they were considered an individual upon their own merits. Thus, it is important for everyone to consider and challenge their stereotypes and assumptions of autistic girls. It is important for individuals to deconstruct their understanding of autism before reconstructing it with knowledge shared by those who can be considered experts in autism, those who are autistic (Gillespie-Lynch et al., 2017; Lester et al., 2014); thus phenomenological research is one way to gain insight into autistic individuals' lived experiences.

5.3.1.2 Heterogeneous Nature. Related to rethinking assumptions, it is important for individuals to appreciate the heterogeneous nature of autism. As Olivia expressed, "*[autistic] girls and boys are different but then also girls and girls can be different*". All participants reflected upon the diverse nature of autism in general, as well as the diversity of experiences between autistic females. This reinforces the recommendation to avoid making assumptions when told an individual is autistic; the label 'autism' does not offer definitive information without understanding the individual's profile of strengths and needs. Autism may identify a difference in how an individual thinks and experiences the world (McCann, 2019), but each individual will have a unique understanding and experience (Eaton, 2019).

5.3.1.3 Promoting Belongingness. Participants' narratives highlighted that it is important to promote feelings of belonging for adolescent autistic girls. Research shows that a sense of belonging can be supported in autistic girls through reciprocal friendships; feeling safe and supported; encouragement and inclusion from peers; and, establishing and adhering to social expectations (Myles et al., 2019). Their sense of belonging should be nurtured to positively impact their psychological wellbeing and identity development.

5.3.1.4 Promoting Agency. All young people need to have a sense of agency or control in their life to develop good self-efficacy and resilience (Rutter, 2013). It is also recognised as a right in the UNCRC (UNICEF, 1989) that all children should be involved in decision-making

processes about their lives. Additionally, adolescent autistic individuals are more likely to interpret their diagnosis as an advantage if they have more agency (Mogensen & Mason, 2015). Because interpreting diagnoses as an advantage is protective of psychological wellbeing and identity (Carrington & Graham, 2001; Cooper et al., 2017; Feist, 2013), it follows that promoting autistic girls' agency could ultimately support their psychological wellbeing and identity development.

5.3.2 Implications for Educational Psychologists

Interestingly, none of the participants in this research mentioned EPs in their narratives. An EP's role is often focused on supporting key adults to better support the individual; therefore the EP's involvement may be undetectable to the individual themselves (Lee & Woods, 2017). Nevertheless, this may also indicate that EPs are not often involved with autistic girls, perhaps due to a lack of academic or behavioral need (Baldwin & Costley, 2016; Such, 2017), this point will be expanded on in the School Level section below. I will consider the implications of this research for EPs, beyond the general implications described above, upon the personal EP, school level and individual student.

5.3.2.1 Personal EP Level. All practicing EPs should be reflexive practitioners (Quicke, 2000) and therefore should strive to be conscious of the impact of their own assumptions and stereotypes. It is important for all EPs to examine their own thinking and assumptions around autistic girls. This research has highlighted the importance of professionals remaining reflexive and to understand the young person's reality so that they are not driven by unfounded assumptions. This research has demonstrated that narrative techniques are one effective way to elicit individuals' personal understanding of autism and the NOI approach effective to provide helpful insights by considering the fabula and sjuzet of narratives.

Furthermore, as is a requirement of the Health and Care Professions Council (the professional regulatory body for EPs), EPs should remain up to date on the current knowledge and understanding offered by research. Whilst some EPs report little access to journals to enable this (Such, 2017), it is vital that EPs, as evidence-based practitioners, use current research to inform strategies and support they facilitate for young people. This is particularly relevant for autistic girls as it is currently a rapidly growing research area.

5.3.2.2 School Level. EPs can support autistic girls through the systemic school level. Raising awareness of autistic girls has already been recognised as a key role for EPs (O'Hagan & Bond, 2019; Such, 2017) and is further contended here. Training staff is of high importance, as well as challenging unhelpful assumptions and stereotypes staff may hold (Grieve, 2009) to create

more inclusive environments in which autistic girls feel comfortab;e and accepted. Specific emphasis should be given to the safeguarding responsibilities of all adults when considering the potential vulnerabilities and consequences of this for autistic females (Bargiela et al., 2016; Kock et al., 2019). Staff should be enabled to adopt a person-centered approach seeing beyond the label of autism and acknowledging that each individual has unique strengths and challenges (Hebron, 2019).

There is also a need for EPs to support schools to prioritise autistic girls and to facilitate a more proactive rather than reactive approach. This should help to combat the unfortunate commonality that autistic girls reach crisis point before receiving support (Zener, 2019), an experience exemplified in some participants' narratives. This should be achieved through the training provided and questions EPs can ask, such as in planning meetings, and drawing attention to the fact that autistic girls may need support even if they appear to be coping and do not have an academic need (Baldwin & Costley, 2016; Such, 2017). Receiving the right specialised support earlier should lead to better psychological wellbeing outcomes, including identity development.

Promoting inclusion is a major role for EPs by supporting schools to develop inclusive cultures that value diversity (Farrell, 2004). This supports every student's sense of belonging within the school (Stewart, 2012). For autistic students, this would include facilitating peer awareness and acceptance of autism (Bond & Hebron, 2019; Humphrey & Symes, 2010; Morewood et al., 2019). Peer awareness and acceptance was very influential in the narratives shared in this research. Furthermore, the autism education that pupils receive can be pivotal for their constructs of autism, as Emily's narrative highlighted. This is also particularly important considering the delayed diagnosis of females because their early understanding of autism will be influenced by their existing education and experience. An EP can encourage these important school initiatives through their work with SENCos and Senior Management. Nevertheless, each school will also have an individual context, therefore what is successful within one setting will not always be transferable. The skill of the EP and the school staff is important for creating a plan that is suitable for individual schools (Such, 2017).

5.3.2.3 Individual Level. Through their narratives all participants highlighted the importance of having the right, individualised support for them. What supported one participant, was not appropriate for all. Person-centered planning is a strengths-based, solution-orientated approach (O'Brien, 2002; Sanderson, 2000) that focuses on the 'whole person' within their context by highlighting strengths and interests alongside areas of need (Bond & Hebron, 2019), and it is

recommended for autistic girls (Honeybourne, 2016). Person-centered planning works *with* young people focusing on co-construction by gathering their views (Bond & Hebron, 2019; O'Hagan & Bond, 2019) as the SEND Code of Practice endorses (Department for Education, 2015). EPs can gather autistic females' views and work with key adults to create a person-centered plan that accounts for their identification with their diagnosis. It is important to involve the girl's family in this process as positive teacher-parent relationships and a joint goal are needed for best outcomes (Bond & Hebron, 2019). This also allows for consideration of the family's culture and the influence this may have upon the individual. Including the parents in the process enables the EP to understand the parent's perspective of autism then reframe, where needed, by challenging any negative, deficit-based discourses (Theara & Abbott, 2015) and by sharing helpful resources.

McCann (2019) proposes five key areas to consider when supporting autistic girls in primary schools, and arguably the same principles can be extended to secondary provision. Below are McCann's key areas of focus whilst integrating insights from participants' narratives. EPs can use McCann's (2019) five areas to guide their involvement.

1. *The environment*. It was previously known that subtle environmental factors have significant impact upon autistic girls (Morewood et al., 2019); this was reflected through the narratives shared. It is important to work with individuals to understand which factors impact them and to consider ways to reduce this. For example, seating plans may need to be considered as was important for Maddison, or the classroom layout as was important for Emily. Nevertheless, adaptations made need to directly address that girl's needs, otherwise they may instead feel like Chloe did in her mainstream secondary, separated, and limited by the support the school implemented.

2. *Sensory and emotional support programmes*. Sensory sensitivities are becoming increasingly recognised as effecting autistic girls, and all participants referred to them in their narratives. For example, describing the discomfort experienced from bright lights, loud noises and crowded classrooms. It is important to consider the smells, colours, noise, patterns, materials etc. present in the environment and how this may impact the individual. Completing sensory audits is one way to consider environmental adaptations (Morewood et al., 2019). Moreover, a trained professional could complete an individual sensory assessment to understand what activities could help manage hyper- or hypo- sensitivities.

   Furthermore, emotional support should be considered. As already discussed, emerging research suggests autistic girls may have better empathy skills than often assumed

(Hadjikhani, 2014; Sucksmith et al., 2013). This was also reflected in Lauren's narrative where she said: "*I'm very very empathetic*". Autistic girls can be overly sensitive to a teacher's frown, may be a 'people-pleaser', and may 'overreact' to negative emotions such as the whole class being told off, as was true for Olivia. Negative emotions can lead to heightened anxiety for an autistic girl who may then begin to internalise those feelings, leading to self-blame (McCann, 2019). Therefore, teaching about emotions and their related internal states is key to developing their self-awareness, which will consequently support the development of coping strategies. Anxiety is particularly common for autistic girls (White et al., 2009), as these participants also expressed. Therefore, support to develop anxiety-management strategies is often necessary. This support and education should be considered proactively, before a crisis point is reached.

3. *Social interactions and friendships.* Difficulties with friendships was a prevailing theme throughout previous literature and this research. However, it also cannot be assumed that autistic girls are socially motivated to seek out friendships – they *may* prefer to be alone. Peers can be both a protective and a risk factor for autistic girls (Bond & Hebron, 2019), therefore support needs to be respectful of this. To support friendships, interventions often draw upon practices that are largely based upon the male body of research. Yet supporting an autistic girl with friendships may be different to supporting autistic boys based upon gender-specific socialisation (Bond & Hebron, 2019). Successful friendship strategies described by these participants included making friends through friends, having an assigned buddy, and developing friendships based upon shared interests.

4. *Educational support and access to learning*. Specialist assessments may be needed to understand the strengths and needs a girl may have in accessing learning, even in the absence of attainment needs. Assessing an individual's executive functioning skills would support understanding of how she accesses learning and therefore how to differentiate her teaching. Often autistic individuals respond well to structure and predictability, such as Olivia and Maddison described (although this is not always true, such as for Emily). This can be provided by telling the girl exactly what is expected in learning activities: for example, how long she should be working for as well as how to know and what to do when finished. This should be communicated using clear, chunked instructions (McCann, 2018). Making these aspects predictable and structured can reduce anxiety enabling the individual to engage in the learning. However, any adaptations should be monitored closely to evaluate effectiveness, whilst also accounting for the girl's views.

5. *Support for growing up.* Promoting developmentally appropriate independence and self-awareness is important for autistic girls. As was pervasive throughout the narratives, developing self-understanding was key to their self-acceptance and coping strategies. Knowledge of their diagnosis and what this means for them was fundamental, as was also found in Molloy and Vasil's (2004) research. All autistic individuals need the opportunity to explore their diagnosis to understand what it means to them and if and how it forms part of their identity (Macleod et al., 2013); narrative techniques have proven useful to do this. Yet as Lauren reflected, having an autism diagnosis as well as being a teenager can be hard. This can be compounded by the social vulnerabilities associated with an autism diagnosis (Bargiela et al., 2016; Cridland et al., 2014). Therefore, autistic girls need to be supported to explore their identity, inclusive of but not exclusively focused upon autism. They may also need explicit teaching to address their social vulnerabilities. This will be important towards them reaching an 'identity achieved' status, which is advantageous for development and psychological wellbeing (Marcia, 1966) whilst enabling them to keep themselves safe.

5.4 Research Evaluation

It is important to evaluate the quality of any research to understand its contribution to knowledge (Barker & Pistrang, 2005). Yet this should be differentiated depending upon the methodology (Tracy & Hinrichs, 2017). This research was qualitative, therefore different qualitative quality criteria were explored. Yardley's (2015) criteria guided this dissertation due to it being well renowned and popular throughout the reviewed literature.

5.4.1 Research Quality Criteria

Below I will discuss each of Yardley's (2015) criteria to consider how they have been addressed.

5.4.1.1 Sensitivity to Context. The inductive nature of this research meant that I remained sensitive to the context of participants' narratives and was able to apply relevant theoretical and empirical literature, but in ways that reflected the heterogeneous experiences. Furthermore, I have reduced (although not eliminated) the impact of researcher and setting characteristics by using narrative interviews, open-ended questions and meeting at participants' choice of venue. During the analysis stage, each analytical step of NOI remains receptive to the context of participants and their narratives, this is particularly exemplified in the final stage when assigning identity positions, as this considered what epistemic right they were drawing on to share that information.

5.4.1.2 Commitment and Rigour. Throughout I have been committed to participants to do their narratives justice and present them accurately. I have also expressed my commitment to my ethical standards by making every effort to ensure the research experience was enjoyable for participants. I have been committed to conducting this research with rigour by engaging extensively and thoroughly with participants throughout multiple meetings. The NOI analysis was purposefully chosen, as described in the Methodology chapter, due to its sophisticated and psychological approach. The discrete steps of NOI and clear instructions (Hiles et al., 2009) allowed a significant level of both depth and breadth of analysis, which can be demonstrated through the working transcripts, adding to the rigour of this research.

5.4.1.3 Coherence and Transparency. Throughout this research, I have remained true to my methodological and ethical position. Nevertheless, every reader will make their own judgement on this research's coherence (Polkinghorne, 2007). The supervision and reflexive practices I have engaged in, such as a reflective diary, have also encouraged me to remain aware of the coherence. This research has strengths in terms of its transparency: the methods of data collection and analysis have been thoroughly described using examples and quotations throughout. Additionally, the appendices included provide evidence of my commitment to transparency. The NOI analysis used also has strengths in its transparency (Hiles & Čermák, 2007). Furthermore, I have addressed my position as a researcher in various places throughout the chapters, and a final reflection will follow in this chapter.

5.4.1.4 Impact and Importance. The impact and importance of this research has been addressed throughout, specifically within the Introduction and Discussion chapters. In summary, there are both conceptual and practical implications arising from this research. Conceptual implications include an improved understanding of adolescent autistic girls' perspectives of autism and exploring how this relates to their identity. In terms of practical implications, multiple recommendations have been made relating to EPs as well as general implications.

There is a call in the literature to raise awareness of autistic girls and their experiences (Baldwin & Costley, 2016; Kirkovski et al., 2013). The insights this research has gleaned will be one important step towards this. Some preliminary key messages from participants' narratives have already been shared at a LA SENCo conference. In the future, these findings will be disseminated through research summaries for participants and SENCos who also expressed interest. The sum of these activities ensures that this research will potentially impact a range of professionals, autistic individuals and their families.

5.4.2 Strengths and Limitations

Beyond the quality criteria discussed, there are also some strengths and limitations to be considered.

A major strength of this research is the inclusive nature adopted. The narrative methodology used aimed to elicit the voices of autistic girls, which have been lacking in research until recently (Steward et al., 2018). Although this is a population that characteristically have social communication difficulties (Milton & Bracher, 2013), this did not seem to impede participants' ability to engage in the narrative interviews. As a researcher I remained flexible and adaptive to participants' needs and was willing to take measures necessary to enable them to share their narrative. For example, the use of visuals and alternative communication methods to provide participants with a range of options. Nevertheless, all participants chose to verbally communicate.

My methodology has also allowed these five participants to be active contributors to the female autism discourse and by sharing their narratives with direct quotations I have privileged their voices above my interpretation. Although not an original intention, this research accessed individuals that are not active in the Autism Community therefore giving them opportunity to add their stories to the available knowledge.

Additionally, the ethical approach of this research is a strength. As a researcher, I wanted to make taking part enjoyable and meaningful for participants and I took many steps to achieve this. The success of this was reflected in participants' comments following the sessions. For example, one participant emailed: "*I really enjoyed our sessions and participating in your research really was a genuine pleasure – it was nice for me to reflect on aspects of my autism again and was therapeutic to talk about*".

Nevertheless, some of the adaptations offered also had potential drawbacks, such as accompanying adult influence upon the narrative shared. Having an accompanying adult present may have influenced what participants did and did not share. Parental influence was considered to be a significant factor for one participant's narrative. It felt apparent that the mother also had a story to tell and wanted to be heard, therefore at times she took control of the narrative. This highlights the importance of an uninterrupted setting, however this is more difficult to guarantee when meeting at participants' homes. There are likely to always be unexpected variables when collecting data in a naturalistic setting (Bryman, 2012; Hiles & Čermák, 2007), therefore researchers need to recognise these as part of the process, but remain aware to their influence

upon the data collected. Yet the ethical reasons for offering the choice of an accompanying adult outweighed the potential drawbacks.

It is important to acknowledge that the narrative approach used privileges participant's perspective and is aiming to understand their interpretations (Polkinghorne, 2007). Throughout I have remained aware of the interpretive nature of NI, and the understanding that narratives are one person's world view. Thus, I have not aimed to present participants' narratives as accurate representations of reality at any point, which can be a common critique of NI research (Atkinson & Delamont, 2006). Furthermore, the potential pressure of presenting themselves in a socially desirable way means that it is possible participants did not share the true complexity of their thoughts and feelings (Polkinghorne, 2007). This may be even more problematic due to the high prevalence of camouflaging within the autistic female population (Hull et al., 2020; Milner et al., 2019; Tierney et al., 2016), which has previously been a limitation (e.g. Carrington et al., 2003). I aimed to reduce the chances of a need to camouflage by increasing their agency in the process through offering them choices, and with conscious efforts to build rapport to aid their comfort and willingness to share.

An additional consideration was the application of identity theory to the narratives. Similar to Feist's (2013) reflections, it cannot be proven whether the identity statuses I interpreted from the narratives are a true reflection of participants' state of identity. To fully understand participants' identity statuses, a longitudinal and multi-method investigation would be needed. Being aware of this limitation, I used Marcia's (1966) identity status theory to support understanding and interpretation but not as a definitive conclusion. This study therefore cannot be used to make predictions about other autistic girls based upon their supporting or hindering experiences and subsequent identity status, but this was also not intended. Instead this research offers analytical generalisability by generating an understanding of a concept that can inform future contexts and populations (B. Smith, 2018); the experiences shared by these participants can inform the type of experiences and quality of relationships that may be supportive, or may hinder an individual's understanding of an autism diagnosis. The knowledge gained may inform approaches and understanding of autistic girls in similar, but not identical, situations.

The final strength to discuss, is the sample size. Whereas in the positivist paradigm a sample size of five would be a limitation, in the interpretivist paradigm with subjectivist epistemology this can be a strength. Coupled with the use of NOI offering a significant depth of analysis, I was able to fully appreciate all narratives. This facilitated a significant depth of perspective into individual

contexts. Nevertheless, if more time had allowed, having more participants whilst still affording each narrative the same depth of analysis would have only enriched this research.

5.5 Future Directions

This research contributes to the understanding of adolescent autistic girls' sense-making processes of their diagnosis. Yet, there are still areas that require further insight.

Further phenomenological research with autistic individuals is necessary to keep professionals' constructions of autism current and representative of those that hold the epistemic rights to define their diagnosis (Gillespie-Lynch et al., 2017). Specifically, further research is needed with autistic females to understand the breadth and heterogeneous nature of their experiences. This is important in itself to increase understanding, but also will begin to balance out the male-bias that currently permeates autistic literature (Haney & Cullen, 2017).

There is also a need to conduct research with autistic individuals with a wider variety of characteristics to begin to understand the variety of experiences. Further recruitment methods should be considered that are inclusive of broader samples to make the literature more representative, which consequently may begin to challenge some of the more prevalent autistic stereotypes. For example, as gender dysphoria is more common within autistic populations than non-autistic populations (Glidden et al., 2016), it would be important to understand the interaction of identification with gender and an autism diagnosis. Within this sample, participants explicitly spoke about the expectations of being female and the influence that has upon their expression of autism; perhaps an individual with gender dysphoria would offer a different perspective. All autistic research should also state the justification for inclusion or exclusion of self-diagnosed autistic individuals, this appropriate inclusion or exclusion may differ depending upon the research aims.

In terms of future research methods, it is important to consider further ways to conduct participatory research with autistic individuals (Leedham et al., 2020; MacLeod et al., 2014; Milton & Bracher, 2013). Future methods should support participants to share their views in a way that they feel comfortable, to increase participation. The more autistic individuals with a broader range of experiences are meaningfully included within research, the less alienated they may feel from the knowledge produced by research (Begon & Billington, 2019). It is important to break down boundaries between what has previously been considered the 'expert' or professional, and 'non-expert insider' or autistic individuals' views through more inclusive and participatory research.

5.6 Reflexive Account

All qualitative researchers must engage in the process of reflexivity to understand their own influence upon their research (Tracy & Hinrichs, 2017; Yardley, 2015). There have been pertinent points of reflection in previous chapters of this dissertation, however now I offer a reflexive account about the research process as a whole.

Conducting this research has been a learning experience for me as a novice researcher working through the intricacies of a doctoral dissertation. I have been motivated throughout to explore the topic for reasons shared in the Introduction chapter, but also driven to respect each participant by ensuring they have a positive experience, as well as providing an authentic voice when communicating their narrative. This has led me to include steps that initially may not be considered necessary, such as an introduction letter with my photograph before the initial meeting or commissioning an artist to draw Emily's description. However, I believe these additional steps were key to this research's success and meant that I could feel confident that what I have presented achieves the aim of communicating their stories.

This dissertation has also in part been a journey of self-discovery. As I noted in my reflective diary: "*I really felt myself relate. Definitely invoked my own memories and experiences of school*". It has interested me to realise how many similar experiences I have had to the participants, which has led to new levels of empathy despite having what may be considered an outsider perspective. This experience has further convinced me of the neurodiversity perspective of autism. The resulting empathy is now something that I can draw on when supporting autistic girls in my practice as an EP.

In the Introduction chapter, I presented the idea that one aim of this dissertation was to challenge professionals' assumptions and stereotypes about autistic girls. Throughout this research I have been deconstructing and beginning to reconstruct my own understanding of autism. Some of my personal assumptions have been challenged as I noted in my reflective diary. For example, I previously thought all autistic individuals preferred routine and predictability; Emily did not, and instead found this a chore. Furthermore, I had not before considered a potential impact of therapy being to *lose* a sense of identity as Lauren described. Nevertheless, I will now consider these in future. It is important for everyone to examine their assumptions in light of these narrative accounts. I am hoping that by disseminating the results of this research, I can encourage others to do the same.

Lastly, I have thoroughly enjoyed meeting the participants and having the opportunity to get to know them and their stories. As I noted in my diary "*I just feel a massive gratitude towards all of the girls I've met, that they've been happy and able to share their stories with me!*". It has been a privilege, and I hope that they feel that I have done them justice in how I have represented them.

5.7 Conclusion

This research aimed to firstly capture the subjective experiences of adolescent autistic girls to consider how they understand their diagnosis, and secondly, what experiences or relationships influenced their identification with their autism. Importantly, all participants reflected upon the diversity of autism highlighting that everyone experiences it differently. The narratives shared by Maddison, Olivia, Chloe, Lauren and Emily indicated that they were mostly active in constructing their own understanding of autism using information from personal research, school lessons, parents, therapy and knowing other autistic individuals. Interestingly, no participant described having a good understanding of autism before their diagnosis and even when researching, they had to search for descriptions that resonated and made sense for them. This research has highlighted that it is important to encourage autistic girls to explore their diagnosis to consider their commitment to an autistic identity, but with the support of a trusted adult such as a parent, teacher or therapist. This research has also indicated that to develop an autism social identity, which has previously been identified as a protective factor (Cooper et al., 2017), it is not essential to engage in the wider Autism Community, although this may help some. Instead, it seems important to help individuals to realise that they are not alone in their diagnosis or experiences, possibly through support groups or by connecting them with other autistic individuals, specifically other girls.

Previous research indicates that best outcomes in terms of identity and psychological wellbeing are seen when an individual has personal agency to identify with their diagnosis (Cooper et al., 2017; Mogensen & Mason, 2015). The narratives in this research suggest that before identifying with their diagnosis, autistic girls needed opportunity to explore their diagnosis whilst experiencing a sense of belonging and reassurance from their family, friendships, and school. Through these experiences it may lead them to conceptualise autism as a difference and not a disability. This is desirable because conceptualising autism as a difference, not a disability is currently understood as beneficial for their psychological wellbeing.

Both conceptual and practical implications from this research have been discussed. Overall, everyone needs to be aware of their assumptions, and respect the heterogeneity of the autistic female population. Belongingness and sense of agency emerged as important for individuals for a positive sense-of-self and identity, inclusive of their diagnosis. Therefore, support and intervention should focus upon these.

For EPs specifically, they need to be aware of a girl's understanding of her diagnosis and support the education staff and parents to help her to explore it. Narrative techniques and person-centered planning are useful to do this effectively. However, as the narratives shared here highlight, support needs to be individualised. Lastly, EPs also need to remain conscious of their own assumptions and stereotypes and ensure that they are person-centered in their practice, listening to and taking account of how individuals construct their autism. It is important to consider the extent to which it forms part of their identity.

5.8 Closing Thoughts

As this research is aiming to put participants' voice at the centre, it is not right that I, as the researcher, have the last word. Therefore, the responses participants gave when asked what they wanted others to understand about autistic girls are the closing thoughts of this dissertation.

It's so different *in* different *people…what they see of autism is not what everyone with autism is like. You might see the most extreme end and then they'll be like, "oo this is what someone's like" and then they'll meet someone and be like "hey, you're not like that"*

(Maddison)

They're just the same as everyone else, they want what people that don't have autism…they want that. And I think the majority of them do, they just don't know how to explain it or don't know how to go about it. They're not like everyone but they want to have the same goals, they want to achieve and do the things other people do. But I just don't think people think that, I think they think that they want to be on their own

(Chloe)

It's not the same as boys we act differently and the signs of it is different. You shouldn't compare it to boys. Not everyone will be the same with it…not everyone will have the same signs and not

everyone will act the same…girls don't show as much, they keep it in and they don't express it as much as boys and that's why boys generally get diagnosed a lot earlier than girls…whereas girls just sort of "oh she's just shy she's fine" but it's not…

(Olivia)

Don't see it as a bad thing…they seem to see it like it's something to worry about or something like that. When someone tells you they have autism it's more like saying, "I'm a perfectionist" or "I'm self-aware" than it is saying "I have depression" or "I have anxiety" because it's more of just a way of being, than it is a thing that's on top of you…it's not an illness it's more of a personality trait, but it's more in the middle

(Emily)

*Just because it's less recognised it doesn't mean it's not valid and that we're not struggling… we just hide it so much better…*I *don't like the thought of people looking at a girl and thinking to themselves "I don't think she's autistic because she seems too normal" or "I do think she's autistic because she's studious and weird" and all those labels what a female with autism looks like. I just think that if you don't know for sure just don't make a judgement. Just treat any,* any *girl, whether you suspect it or not, just like everyone else because we are normal, we just have a different wiring.*

(Lauren)

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7 Appendices

Appendix A: Systematic Literature Search PRISMA Flowchart and List of Papers Reviewed

Appendix B: Form Completed for Ethical Consent

Appendix C: Participant Consent Form

Appendix D: Parent/Carers Consent Form

Appendix E: Advert for Recruitment

Appendix F: Information Sheet for Participants

Appendix G: Information Sheet for Parents/Carers

Appendix H: Narrative Interview Guide

Appendix I: ‘Stop’, ‘Skip’, ‘Break’ visual cards

Appendix J: Life-Grid

Appendix K: 25 Dixit® Cards

Appendix L: Lauren’s Visual Timeline for Analysis and Feedback Session

Appendix M: Olivia’s Dixit® Card Feedback

Appendix N: Chloe’s Quotation Feedback Visual

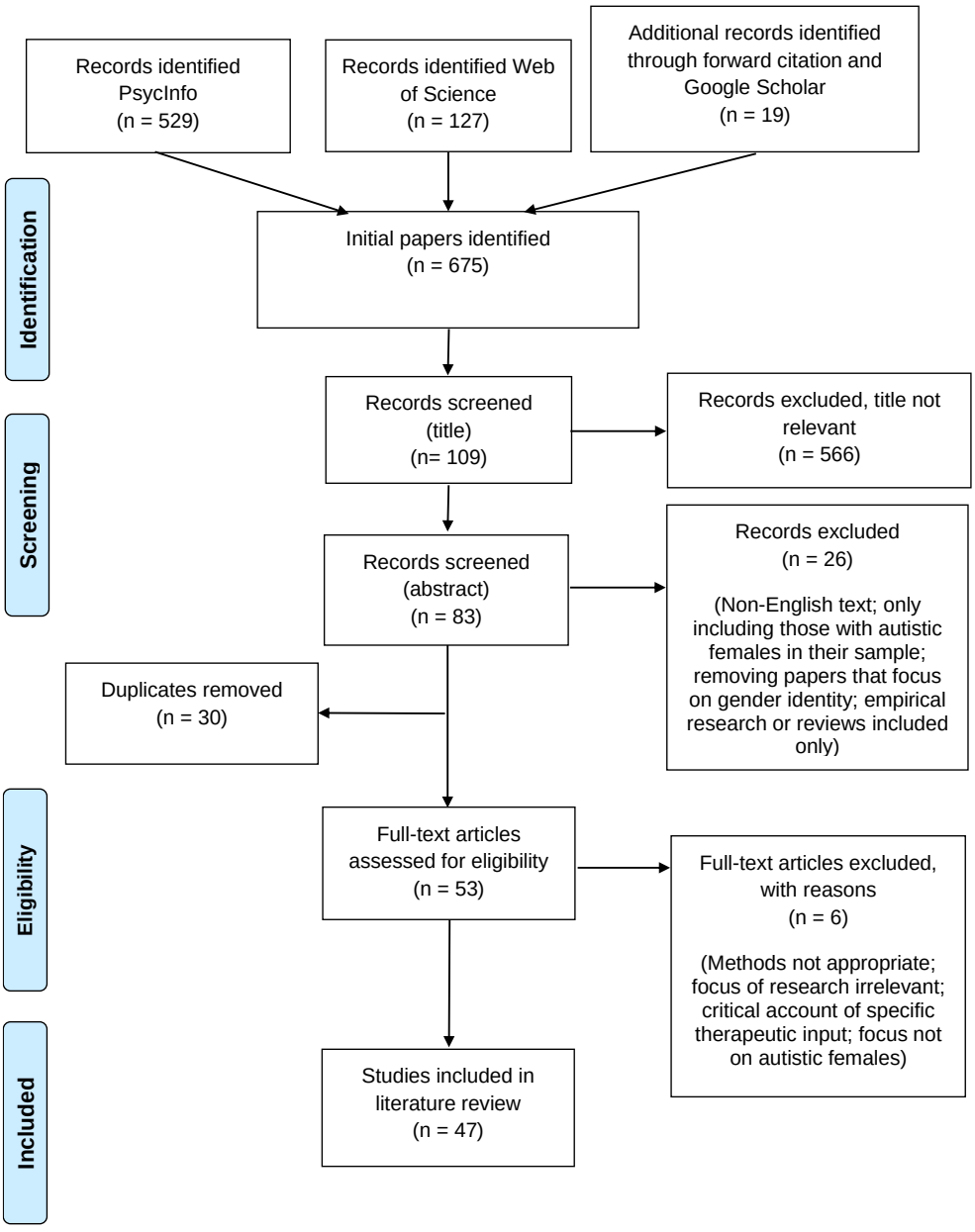
Appendix O: A Sample of Emily’s Working Transcript

Appendix P: Maddison’s Categorical-Content Analysis Tables

Appendix A: Systematic Literature Search PRISMA Flowchart

Systematic Search in PsycInfo and Web of Science on 13th December 2019 and repeated on 2nd April 2020.

Search terms used: (Wom#n OR girl* OR female*) and (Identity OR self#concept OR self#perception OR experience*) and (Autis* OR ASD OR ASC OR Asperg*)



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Gaffney, J. C. (2017). “It’s autism, it’s just a name”: Exploring the impact of autism spectrum diagnosis with adolescent females using interpretative phenomenological analysis [Unpublished doctoral dissertation]. The University of Sheffield.

Logsden, L. (2010). The experiences of adolescence for females with asperger’s disorder [Unpublished doctoral dissertation]. Alliant International University.

Rainsberry, T. (2016). An exploration of the positive and negative experiences of teenage girls with autism attending mainstream secondary school [Unpublished master's thesis]. The University of Birmingham.

Appendix B: Form Completed for Ethical Consent

SPS RESEARCH ETHICS

APPLICATION FORM: STAFF and DOCTORAL STUDENTS

- This proforma must be completed for each piece of research carried out by members of the School for Policy Studies, both staff and doctoral postgraduate students.
- See the Ethics Procedures document for clarification of the process.
- All research **must** be ethically reviewed before any fieldwork is conducted, regardless of source of funding.
- See the School's policy and guidelines relating to research ethics and data protection, to which the project is required to conform.
- Please stick to the word limit provided. **Do not attach** your funding application or research proposal.

Key project details:

1.	**Proposer's Name**	Heather Carver		
2.	**Proposer's Email Address:**	*hc17885@bristol.ac.uk*		
3.	**Project Title**	*What is it like to be a female and have autism?*		
4.	**Project Start Date:**	*May 2019*	**End Date:**	*September 2020*

Who needs to provide Research Ethics Committee approval for your project?

The SPS REC will only consider those research ethics applications which do not require submission elsewhere. As such, you should make sure that your proposed research does not require a NHS National Research Ethics Service (NRES) review e.g. does it involve NHS patients, staff or facilities – see http://www.hra-decisiontools.org.uk/ethics/

If you are not sure where you should apply please discuss it with either the chair of the Committee or the Faculty Ethics Officer who is based in RED.

Social care research projects which involve NHS patients, people who use services or people who lack capacity as research participants need to be reviewed by a Social Care Research Ethics Committee (see https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/social-care-research/). Similarly research which accesses unanonymised patient records (without informed consent) must be reviewed by a REC and the National Information Governance Board for Health and Social Care (NIGB).

Who needs to provide governance approval for this project?

If this project involves access to patients, clients, staff or carers of an NHS Trust or Social Care Organisation, it falls within the scope of the Research Governance Framework for Health and Social. You will also need to get written approval from the Research Management Office or equivalent of each NHS Trust or Social Care Organisation.

When you have ethical approval, you will need to complete the research registration form:

http://www.bristol.ac.uk/red/research-governance/registration-sponsorship/study-notification.html

Guidance on completing this form can be found at: http://www.bristol.ac.uk/red/research-governance/registration-sponsorship/guidance.pdf. Contact the Research Governance team (research-governance@bristol.ac.uk) for guidance on completing this form and if you have any questions about obtaining local approval.

Do you need additional insurance to carry out your research?

Whilst staff and doctoral students will normally be covered by the University's indemnity insurance there are some situations where it will need to be checked with the insurer. If you are conducting research with: Pregnant research subjects or children under 5 you should email: insurance-enquiries@bristol.ac.uk

In addition, if you are working or travelling overseas you should take advantage of the university travel insurance (see http://www.bristol.ac.uk/secretary/insurance/travel-insurance/).

Do you need a Disclosure and Barring Service check?

The Disclosure and Barring Service (DBS) replaces the Criminal Records Bureau (CRB) and Independent Safeguarding Authority (ISA). Criteria for deciding whether you require a DBS check are available from:

https://www.gov.uk/government/organisations/disclosure-and-barring-service/about

You should specifically look at the frequency, nature, and duration of your contact with potentially vulnerable adults and or children. If your contact is a one-off research interaction, or infrequent contact (for example: 3 contacts over a period of time) you are unlikely to require a check.

If you think you need a DBS check then you should consult the University of Bristol web-page:

http://www.bristol.ac.uk/secretary/legal/dbs/

5. If your research project requires REC approval elsewhere please tell us which committee, this includes where co-researchers are applying for approval at another institution. Please provide us with a copy of your approval letter for our records when it is available.

n/a

6.	Have all subcontractors you are using for this project (including transcribers, interpreters, and co-researchers not formally employed at Bristol University) agreed to be bound by the School's requirements for ethical research practice?	
Yes		
No/Not yet		Note: You must ensure that written agreement is secured before they start to work. They will be provided with training and sign a detailed consent form.
Not applicable	**x**	

7.	If you are a PhD/doctoral student please tell us the name of your research supervisor(s).	
Dr Robert Green and Dr Amanda Gaulter		
Please confirm that your supervisor(s) has seen this final version of your ethics application?		
Yes	**x**	
No		

8.	Who is funding this study?
n/a	

If this study is funded by the ESRC or another funder requiring lay representation on the ethics committee and is being undertaken by a member staff, this form should be submitted to the Faculty REC.

Post-graduate students undertaking ESRC funded projects should submit their form to the SPS Research Ethics Committee (SPS REC).

9.	Is this application part of a larger proposal?	
No	**x**	
Yes		

If yes, please provide a summary of the larger study and indicate how this application relates to the overall study.

10. Is this proposal a replication of a similar proposal already approved by the SPS REC? Please provide the SPS REC reference number.

No	**x**
Yes	

If Yes, please tell us the name of the project, the date approval was given and code (if you have one).

Please describe any differences (such as context) in the current study. If the study is a replication of a previously approved study. Submit these first two pages of the form.

ETHICAL RESEARCH PROFORMA

The following set of questions is intended to provide the School Research Ethics Committee with enough information to determine the risks and benefits associated with your research. You should use these questions to assist in identifying the ethical considerations which are important to your research. You should identify any relevant ethical issues and how you intend to deal with them. Whilst the REC does not comment on the methodological design of your study, it will consider whether the design of your study is likely to produce the benefits you anticipate. **Please avoid copying and pasting large parts of research bids or proposals which do not directly answer the questions.** Please also avoid using *unexplained* acronyms, abbreviations or jargon.

1. **IDENTITY & EXPERIENCE OF (CO) RESEARCHERS:** Please give a list of names, positions, qualifications, previous research experience, and functions in the proposed research of all those who will be in contact with participants

Name Heather Carver

Position Trainee Educational Psychologist

Role in research I will be conducting all parts of the research project, design, data collection, analysis and write up

Qualifications

- 1st Class BSc (Hons) Psychology (University of Bath, July 2014)

Previous Research Experience

Previous research experience includes small projects both qualitative and quantitative research as part of the research methods module at the University of Bath. I also completed my undergraduate dissertation which was a quantitative investigation into the visual acuity of boys with autism. I completed this research independently.

I have also undertaken a paired research commission in my first year of the doctoral course at University of Bristol. Which was investigating how Somerset Educational Psychologists collect the views of Post-16 students during the statutory process. This was a qualitative research project using questionnaires and analysed with thematic analysis.

2. STUDY AIMS/OBJECTIVES [maximum of 200 words]: Please provide the aims and objectives of your research.

This study will aim to gather the narratives of females with autism to determine how they identify with their label of autism (inclusive of all autistic spectrum disorders, Asperger's, pervasive developmental disorder etc.). This is with the aim to understand some of the variety of reactions specifically of females to receiving this male-centric diagnosis.

It is now widely acknowledged that females with autism are not identified as readily as males. Instead they are often misdiagnosed, or diagnosed late meaning that they don't receive suitable support which can have detrimental consequences. However the current understanding of autism and the behavioural presentation is male-centric. Therefore I am interested to explore what females think about being diagnosed with this label as this has not been specifically studied with females before.

A long term aim (although not necessarily directly from only this project) would be to go towards informing a psychoeducational intervention that can be worked through with girls when they are diagnosed to support their thinking around what it means to be autistic. This would hopefully support their social, emotional and mental health needs around accepting or coming to terms with a potentially identity-changing diagnosis.

RESEARCH WITH HUMAN PARTICIPANTS

(If you are undertaking secondary data analysis, please proceed to section 11)

3. RESEARCH METHODS AND SAMPLING STRATEGY [maximum of 300 words]: Please tell us what you propose to do in your research and how individual participants, or groups of participants, will be identified and sampled. Please also tell us what is expected of research participants who consent to take part (Please note that recruitment procedures are covered in question 8)

Participants will be females with a diagnosis of autism that they are aware of and happy to communicate about in English (verbally, written or otherwise), between the ages of 12 years and 19 years old. I am aiming to keep the sample as inclusive as possible, therefore there are no further inclusion or exclusion criteria (i.e. I will accept participants with co-morbid conditions).

Purposive sampling will happen through a couple of avenues:

1. Through link Educational psychologists in my placement team making their school SENCos aware of the research project and the SENCos approaching the girls they think may be interested with the advert and/or information sheets.
2. I will make contact with local support groups for children and young people with autism to discuss the appropriateness of sending them further information or me going to meet with them and/or the children and young people they work with. If they agree, I will send the recruitment sheet along with the information sheets to the autism support groups for them to share with the girls accessing their support. I will also offer to attend a session to be available to explain the research and be available for questions.

If the girls are interested they are asked to talk to their parents/carers and then contact me to ask further questions and/or arrange the initial visit. Therefore this is using an opt-in system for participation.

4. EXPECTED DURATION OF RESEARCH ACTIVITY: Please tell us how long each researcher will be working on fieldwork/research activity. For example, conducting interviews between March to July 2019. Also tell us how long participant involvement will be. For example: Interviewing 25 professional participants for a maximum of 1 hour per interview.

In line with the methodology chosen (narrative inquiry) I will be meeting with between 4-6 participants between 3-5 times.

The location for the meetings will be negotiated with parent, child and school/support group staff as I will offer a choice of spaces at their home, in their school (if their school are in agreement) or at the Educational Psychology office.

Visit 1 - 'Get to know me' session (May – June 2019) - The first visit with the participant will be to build rapport, no data gathering will happen during this visit other than demographic information. I will introduce myself, my role and a bit of my background. I will also prepare them for the next visit and ask for their preference of how to communicate with me for the next visit if I did not manage to establish this for the first visit (verbally, written, typed). I would expect this visit to take about 30 minutes, but up to an hour. This initial visit will conclude with me checking they are willing to continue with the research project and get the necessary consent forms signed.

Visits 2 – 4 Discussion session/s (May – September 2019): These visits will be to collect the girl's narrative in sessions that are no longer than an hour each. I will let the participants know that it is their choice of how many sessions I come back for to ensure they complete their narrative (between 1 – 3). At the beginning of each visit I will re-establish consent, and at the end I will ensure to make it clear when I will be seeing them again. These sessions will be recorded on a Dictaphone.

In between these visits I will analyse the data.

Final visit (February - March 2020): This visit will be when I present the narrative back to the participant in a story form. This will be to double check my interpretation with them to ensure validity of the study. I will also leave a copy of the story with them so that they have something that they produced to take away from the study. This visit will not be recorded, but their comments will be written down to include in the write-up.

5. POTENTIAL BENEFITS AND TO WHOM: [maximum 100 words] Tell us briefly what the main benefits of the research are and to whom.

Participants - Although it will not be therapy, people can often find that telling 'their story' to an interested listener is therapeutic. This story will be presented back to them during the final visit for them to keep so they have something concrete out of the experience.

Professionals working with autistic females, including educational psychologists - This is through increased understanding of some of the reactions and implications of being diagnosed.

There is potential benefit to future females diagnosed with autism through the psychoeducational intervention that I hope to develop that this research will inform.

6. POTENTIAL RISKS/HARM TO PARTICIPANTS [maximum of 100 words]: What potential risks are there to the participants and how will you address them? List any potential physical or psychological dangers that can be anticipated? You may find it useful to conduct a more formal risk assessment prior to conducting your fieldwork. The University has an example risk assessment form and guidance : http://www.bristol.ac.uk/safety/media/gn/RA-gn.pdf and http://www.bristol.ac.uk/safety/policies/

RISK	HOW IT WILL BE ADDRESSED
Participants are children and cannot provide their own consent (under 16 years old).	Parents will be contacted for informed consent (see appendices). The young person will also be asked to provide consent to ensure they are voluntarily taking part. Participant consent will be reaffirmed at the beginning of each session.
Participants may share something that is potentially harmful to themselves or others	The information sheet and consent form will warn of the limits of confidentiality and I will verbally remind participants of this at the beginning of each session with them.
Participants may feel pressurised to share sensitive information and feelings	The information sheet makes it clear that participation is voluntary (see appendices). I will use the first session to build rapport with participants so that they have the chance to know me before sharing any sensitive information they may wish to. I will ensure that I am aware of helpful and able to signpost to websites and agencies, such as counselling services available to them, should they feel it is necessary following participation. Participants will have the option to 'skip' any question if they feel they don't want to answer. This will be made clear to participants prior to each session and they will be provided with a card that they can point to or put on the table to indicate their choice to skip if they do not want to verbalise this choice.
Participants may experience anxiety through participation	I will give participants agency to choose their preferred method of communication for the sessions: face-to-face speech, writing or drawing.

(especially as is a common comorbidity of autism)	I will allow participants in discussion with their parents if under 16 to choose the venue of the sessions so that they can choose an appropriate environment for themselves. Choices offered will be: participant's home, school (if school can support this) or Educational Psychology Service office. Participants will be able to choose to have someone else in the room with them such as a parent to reduce anxiety. Multiple visits will allow participants to become familiar with me and with the type of conversation/communication that we will share. This familiarity would hopefully reduce anxiety. This will be further supported by giving the participants the choice of how many of these sessions we have (ranging from 1 – 3). Participants will be reminded of the opportunity to stop the interview at any point at the beginning of each session. They will provided with a 'stop' card if they do not wish to verbalise this choice. To reduce anxiety during face-to-face sessions I will begin by using visual resources that we work on collaboratively. This means there is less direct attention on them and there is no expectation of eye contact. These resources can be used throughout the sessions, or if the participant chooses to talk instead, I will do this. I will be led by the participant's engagement.
There is the potential participants may be unaware of their diagnosis or have not had such open discussions about it before	I will ensure that the recruitment information make it clear that I am only requesting participants that are comfortable to talk about their diagnosis and are already aware of their diagnosis. If at any point I think the participant is becoming uncomfortable, I will redirect the conversation to more neutral topics. I will then also reaffirm that they want to carry on with the session and the project as a whole. In that conversation I will remind them that participation Is voluntary and they can withdraw if they want to with no consequence.
Participants may become upset during the interview/sessions	During the first session I will ask participants what they would find comforting if they become upset during the process. This may include options of someone to ask to come and see them, time to calm themselves down, having a drink. If they become upset I will cease the interview immediately and use my skills as a Trainee Educational Psychologist to comfort and calm them. It will then be their choice whether to continue or end the interview for that session or exercise their right to withdraw completely. I will also provide the option to each participant to have a reflective journal that they can use to write/draw in in-between sessions if they feel this might help them. I will make it clear to them that these journals will be for their use only and will not be analysed.
Participants have the potential to feel offended by use of language around their autism	I will check with participants what language they would like me to use such as 'autistic female', 'female with autism', ASD/Asperger's etc. The literature

label (or any other labels they may hold)	suggests identity-first language is preferred by autistic people; therefore that will be my default language unless they express otherwise. I will ensure I use their preferred language both during sessions with them and during analysis and creating their stories.
Participants may feel invalidated or misheard	Throughout the sessions I will be using my skills as a Trainee Educational Psychologist to be communicating with them. This includes active listening skills. I will be reflecting back to them what I have heard and understood to gauge if my understanding is correct. To validate their stories, I will use the last session to ensure that I have gathered their views respectfully and have not misrepresented them.
Due to the idiographic nature of the research, participants may be identifiable	Pseudonyms (chosen by the participants from a choice of 3 names I offer them) will be used during write up. Any distinguishing features will be omitted from the write-up.
Interviews will be recorded for transcription following	Participants will be made aware that their interviews will be recorded and kept in lines with data protection regulations. They will sign their consent for this on the consent form. They will also be reminded of their right to withdraw via the information sheet and consent form and if they choose to exercise this, the data will be destroyed.
Recordings of interviews being kept incorrectly.	Data will be stored in audio files on the University of Bristol secure server until they are fully transcribed. Once transcribed, the audio files will be destroyed.
Safeguarding - Participants will be meeting with a new adult, possibly in a quiet separate room	The information sheet will contain information about myself and the fact that I am DBS checked and able to work with children. I will take the safeguarding precautions expected of a new adult meeting a child: making sure the door has a window in it through which we can be seen throughout, or leaving the door propped open.
Participants may miss lessons in school whilst taking part	If participants are happy to meet in school and schools are also agreed, I will organise with schools times that cause least disruption to the participants' education. I will be flexible and happy to meet after school if preferred by the participant. It is noted that I will be meeting participants between 3 and 5 times, I will endeavour to ensure this does not cause them to miss the same lessons each time if during the school day. Particularly for any participants in exam years I will hold the interviews outside of exam periods.

*Add more boxes if needed.

7. RESEARCHER SAFETY [maximum of 200 words]: What risks could the researchers be exposed to during this research project? If you are conducting research in individual's homes or potentially dangerous places then a researcher safety protocol is mandatory. Examples of safety protocols are available in the guidance.

RISK	HOW IT WILL BE ADDRESSED
Interviews may be held in participants' homes	Warwickshire EPS home visit policy will be followed. I will agree a 'buddy' with someone from the EPS who is available at the time I will should be finishing my visit. My buddy will be made aware what time I arrive and what time I expect to be leaving. I will contact them when I have finished. If no contact is made within the expected time frame they will call me. If there is no answer, they will access confidential address details I have provided in a sealed envelope and inform the police.
Safeguarding – as I will be working possibly alone with children and young people, I am open to allegations.	I have an enhanced DBS check I will ensure another adult is nearby If in a room alone with participant, I will ensure there is a window in the door, or leave it propped open
I may become emotional/upset through the process	I will practise good self-care I will only conduct one or two interviews in any one day I will keep a reflective journal throughout the process I will be attuned to my own emotional state throughout I will also access regular supervision throughout the research process
Role confusion as both researcher and trainee educational psychologist	I will be clear to everyone involved that I am assuming the researcher role. However if the participant becomes distressed during the process, the skills I have as a Trainee Educational Psychologist will be used.

8. RECRUITMENT PROCEDURES [maximum of 400 words]: How are you going to access participants? Are there any gatekeepers involved? Is there any sense in which respondents might be "obliged" to participate (for example because their manager will know, or because they are a service user and their service will know), if so how will this be dealt with.

Recruitment will happen in Warwickshire where I am currently on placement as a Trainee Educational Psychologist. School's Special Educational Needs co-ordinators (SENCos) will be approached by their link educational psychologist with the recruitment sheet and information sheets. SENCos will be encouraged to contact myself if they need any clarification or have any further questions. The SENCos then identify any girls in their school that they feel may be interested. The SENCo will share the recruitment sheet with the girl and if interested send the information sheets and consent forms home for herself and her parents to look through and discuss. On this information sheet will be my contact details for them to approach me if they feel interested and return the form or want further information.

An alternative option is for them to return their consent forms to their school SENCo who will then return it to me.

The same recruitment sheet will be distributed to autism support groups in the local area with the same follow up steps. An identified staff member of the group will be the identified gatekeeper.

As the recruitment process will have an 'opt-in' system, the hope is that no one will feel obliged to take part.

9. **INFORMED CONSENT [maximum of 200 words]:** How will this be obtained? Whilst in many cases written consent is preferable, where this is not possible or appropriate this should be clearly justified. An age and ability appropriate participant information sheet (PIS) setting out factors relevant to the interests of participants in the study must be handed to them in advance of seeking consent (see materials table for list of what should be included). If you are proposing to adopt an approach in which informed consent is not sought you must explain in detail why this is not considered to be appropriate. If you are planning to use photographic or video images in your method then additional specific consent should be sought from participants.

Fully informed consent will be gathered from both participants themselves and their parents for participants under 16 years. Written consent will be obtained from both with consent forms (see appendices) following the 'get to know me' session. Participant consent will be verbally reaffirmed at the beginning of each session. On all information sheets my contact details will be clear for anyone to make contact with me to ask any further questions at any point.

Please tick the box to confirm that you will keep evidence of the consent forms (either actual forms or digitally scanned forms), securely for twenty years.	x

10. If you intend to use an on-line survey (for example Survey Monkey) you need to ensure that the data will not leave the European Economic Area i.e. be transferred or held on computers in the USA. Online Surveys (formally called Bristol Online Surveys) is fully compliant with UK Data Protection requirements – see https://www.onlinesurveys.ac.uk/

Please tick the box to confirm that you will not use any on-line survey service based in the USA, China or outside the European Economic Area (EEA).	n/a

11. **DATA PROTECTION**: All applicants should regularly take the data protection on-line tutorial provided by the University in order to ensure they are aware of the requirements of current data protection legislation.

University policy is that "personal data can be sent abroad if the data subject gives unambiguous written consent. Staff should seek permission from the University Secretary prior to sending personal data outside of the EEA".

Any breach of the University data protection responsibilities could lead to disciplinary action.

Have you taken the mandatory University data protection on-line tutorial in the last 12 months?
https://www.bris.ac.uk/is/media/training/uobonly/datasecurity/page_01.htm

Yes	**x**
No	

Do you plan to send any information/data, which could be used to identify a living person, to anybody who works in a country that is not part of the European Union?
See https://ico.org.uk/for-organisations/data-protection-and-brexit/data-protection-if-there-s-no-brexit-deal/the-gdpr/international-data-transfers/)

No	**x**	
Yes		If **YES** please list the country or countries:

Please outline your procedure for data protection. It is University of Bristol policy that interviews must be recorded on an encrypted device. Ideally this should be a University owned encrypted digital recorder (see http://www.bristol.ac.uk/infosec/uobdata/transcription/).

If you lose research data which include personal information or a data breach occurs, you MUST notify the University immediately. This means sending an e-mail to data-protection@bristol.ac.uk and telling your Head of School. See additional details at http://www.bristol.ac.uk/secretary/data-protection/data-breaches-and-incidents/

The UK Data Protection Act (2018) include potential fines of up to €20,000,000 for not protecting personal data – so please provide details about how you plan to ensure the protection of ALL research data which could be used to identify a living person.

Data will be downloaded from the encrypted recording device and saved on the password protected University of Bristol server as soon as is possible following the interview and deleted from the recording device.

Once transcription has taken place, the digital recordings will be destroyed as this will have original names in. The anonymously transcribed data will then be stored securely on the University of Bristol server at open access level for 20 years as PDFs.

Consent forms will be scanned into the University of Bristol server and the paper copies will be destroyed in confidential waste.

Pseudonyms, chosen by participants from a choice of 3 names I offer them, will be used to ensure their data is not identifiable. Files will be saved with the pseudonym name, not the participants' real name.

In between sessions of data collection, anything that is produced during the sessions will be kept in a secure locker in the Educational Psychology Service office to which only I have the key. Furthermore, anything that is created by the girls during the sessions, such as drawings or written information will be scanned in and stored on the University of Bristol Server for as long as analysis is taking place. The paper copies will be disposed of in confidential waste. Following analysis, this information will be destroyed.

I will ensure I clear the data from my sat nav following all visits.

Any email correspondence with participants and/or their parents will be stored on my password protected Warwickshire Educational Psychology Service email account, and this will be deleted after data analysis.

In the event that a participant wishes to withdraw from the study. Their assigned pseudonym will be used to identify all of the relevant information. All information will be deleted along with email correspondence, interview recordings and transcripts. Any paper that is not already, will be destroyed in confidential waste.

12. CONFIDENTIALITY AND ANONYMITY	Yes	No
All my data will be stored on a password protected server	x	
I will only transfer unanonymised data if it is encrypted. (For advice on encryption see: http://www.bristol.ac.uk/infosec/uobdata/encrypt/device/)	X	
If there is a potential for participants to disclose illegal activity or harm to others you will need to provide a confidentiality protocol.	X	
Please tick the box to **CONFIRM** that you warned participants on the information and consent forms that there are limits to confidentiality and that at the end of the project data will be stored in a secure storage facility. https://www.acrc.bris.ac.uk/acrc/storage.htm	x	

Please outline your procedure for ensuring confidentiality and anonymity.

Confidentiality agreement will be addressed through the information sheet which will explain that what we discuss will remain confidential and unidentifiable to them during write-up. It will explain that if they wish to withdraw their information, or any part of it, they just need to contact me.

The limits of confidentiality will also be explained, I will make it clear that if they indicate that themselves or anyone else is at risk of harm. I will need to tell an appropriate person (in lines with safeguarding procedures), but I will also inform the participant if I will need to do that. This is made clear in the information sheet and consent form, and participants will be verbally reminded of this at the beginning of each session.

Pseudonyms, chosen by participants from a choice of 3 that I offer them, will be used to protect participants' anonymity for write up. Participant personal information (such as name, email address and phone number) will be stored in a password protected excel spreadsheet on the University of Bristol server. This document will be the only place where the pseudonym and participant real name will be linked. This document will be destroyed at the conclusion of the dissertation write up. Email addresses will only be stored if a participant wishes to receive a summary of results at the end of the study

Other distinguishing features within their interviews will also be anonymised, such as names of places and other people.

Transcription will be carried out by myself to ensure participants' confidentiality and anonymity.

DATA MANAGEMENT

13 Data Management

It is RCUK and University of Bristol policy that all research data (including qualitative data e.g. interview transcripts, videos, etc.) should be stored in an anonymised format and made freely and openly available for other researchers to use via the data.bris Research Data Repository and/or the UK Data Archive. What level of future access to your anonymised data will there be:

- Open access?
- Restricted access - what restrictions?
- Closed access - on what grounds?

This raises a number of ethical issues, for example you MUST ensure that consent is requested to allow data to be shared and reused.

Please briefly explain;

1) How you will obtain specific consent for data preservation and sharing with other researchers?
2) How will you protect the identity of participants? e.g. how will you anonymise your data for reuse.
3) How will the data be licensed for reuse? e.g. Do you plan to place any restrictions on the reuse of your data such as Creative Common Share Alike 2.0 licence (http://creativecommons.org/licenses/by-sa/2.0/uk/)
4) Where will you archive your data and metadata for re-use by other researchers?

- Consent for data preservation will be gained via the consent forms given to participants and parents. I will also go through these forms verbally with participants to ensure they understand where the data will be stored.
- Participants' identity will be protected by the use of pseudonyms.
- I will not identify the schools or support groups the research was carried out in and will ensure that any information that could make a participant identifiable is kept out of the transcripts.
- I do not aim to place restrictions on the data.
- Data will be archived on the University of Bristol server.

SECONDARY DATA ANALYSIS

14. Secondary Data Analysis

Please briefly explain (if relevant to your research);

(1) What secondary datasets you will use?
(2) Where did you get these data from (e.g. ESRC Data Archive)?
(3) How did you obtain permission to use these data? (e.g. by signing an end user licence)
(4) Do you plan to make derived variables and/or analytical syntax available to other researchers? (e.g. by archiving them on data.bris or at the UK Data Archive)
(5) Where will you store the secondary datasets?

n/a

PLEASE COMPLETE FOR ALL PROJECTS

15. DISSEMINATION OF FINDINGS [maximum 200 words]: Are you planning to send copies of data to participants for them to check/comment on? If so, in what format and under what conditions? What is the anticipated use of the data, forms of publication and dissemination of findings etc.? .

I will take the participants' story back to them to comment on during the final meeting I have with them. This will be in a story format that I have created from what they shared with me during the sessions. During this final session we will read through it together to check that they are happy with how I have written it, and I will invite them to edit it before I include it in my final write up.

The findings will be written up as a full dissertation to be submitted for my Doctorate in Educational Psychology.

I will contact participants and parents with an accessible summary of the research and findings following the write-up.

I will offer to present my findings back to the schools and support groups that were involved as gatekeepers. I will also present my findings to Warwickshire Educational Psychology Service.

I would like to also consider publishing the findings as an article in a relevant British Journal.

16. ADDITIONAL INFORMATION: Please identify which of the following documents, and how many, you will be submitting within your application: Guidance is given at the end of this document (appendix 1) on what each of these additional materials might contain.

Additional Material:	**NUMBER OF DOCUMENTS**
Participants information sheet (s)	3
Consent form (s)	2
Confidentiality protocol	(within PIS and consent form)
Recruitment letters/posters/leaflets	1
Photo method information sheet	n/a
Photo method consent form	n/a
Support information for participant	n/a
3rd party confidentiality agreement	n/a

Please DO NOT send your research proposal or research bid as the Committee will not look at this

SUBMITTING AND REVIEWING YOUR PROPOSAL:

- To submit your application you should create a single PDF document which contains your application form and all additional material and submit this information to the SPS Research Ethics Administrator by email to sps-ethics@bristol.ac.uk
- If you are having problems with this then please contact the SPS Research Ethics Administrator by email (sps-ethics@bristol.ac.uk) to discuss.
- Your form will then be circulated to the SPS Research Ethics Committee who will review your proposal on the basis of the information provided in this single PDF document. The likely response time is outlined in the 'Ethics Procedures' document. For staff applications we try to turn these around in 2-3 weeks. Doctoral student applications should be submitted by the relevant meeting deadline and will be turned around in 4 weeks.
- Should the Committee have any questions or queries after reviewing your application, the chair will contact you directly. If the Committee makes any recommendations you should confirm, in writing, that you will adhere to these recommendations before receiving approval for your project.
- Should your research change following approval it is your responsibility to inform the Committee in writing and seek clarification about whether the changes in circumstance require further ethical consideration.

Failure to obtain Ethical Approval for research is considered research misconduct by the University and is dealt with under their current misconduct rules.

Chair:	Dave Gordon (dave.gordon@bristol.ac.uk)
Administrator:	Hannah Blackman (sps-ethics@bristol.ac.uk)
Date form updated by SPS REC:	January 2018

Appendix C: Participant Consent Form

Informed consent for taking part in '*What is it like to be a female and have autism?*'

Research being carried out by Heather Carver, University of Bristol

Your Name:

Date of Birth:

Please tick the relevant box below

Taking part in the study	Yes	No
I have read and understood the information sheet and have had the chance to ask questions	☐	☐
I understand that I don't have to take part if I don't want to	☐	☐

Use of information in the study	Yes	No
I understand that the things I say will be included in the finished research study and this may be published	☐	☐
I understand that the things we talk about will be recorded	☐	☐
I agree that what I say can be quoted in the write-up (with no names of people or places)	☐	☐
I understand that my information will be kept securely and confidentially (cannot be linked back to me)	☐	☐

Safeguarding	Yes	No
I understand that if I say anything that makes Heather think that I am at risk of harm, she will have to tell someone for my safety	☐	☐

Future use and reuse of the information by others	Yes	No
I give permission for my anonymised transcriptions of interviews (the type up of what I said with no identifiable names) to be saved on the University of Bristol server for future research and learning.	☐	☐
I would like to take part in the interviews	☐	☐

Signature _____ **Date** _____

Please provide details for me to contact you on (please provide parents details if you are under 16):

These are my parent's details

Yes	No
☐	☐

Phone number……

Email ……

Appendix D: Parent/Carers Consent Form

Informed consent for taking part in '*What is it like to be a female and have autism?*'

Research being carried out by Heather Carver, University of Bristol

Name of your child:

Date of birth:

Please tick the relevant box below

Taking part in the study	Yes	No
I have read and understood the information sheet for the above study and have had the opportunity to ask questions	☐	☐
I understand that my child's participation is voluntary and she can change her mind about participating, without given reason.	☐	☐
I give consent for my child to take part in the research project.	☐	☐

Use of information in the study	Yes	No
I give consent for the interview to be digitally recorded.	☐	☐
I understand that what my child says will be reported and quoted in the research and the research may be published	☐	☐
I understand that the information will be kept securely and confidentially and all information will be anonymised	☐	☐

Safeguarding	Yes	No
I understand that if my child shares information that Heather thinks puts her at risk of harm, she will have to inform another professional as part of her limits of confidentiality	☐	☐

Future use and reuse of the information by others	Yes	No
I give permission for my daughter's transcribed interview to be stored on the University of Bristol research server so that it can be used for future research and learning	☐	☐

Parent/Carer name (Printed)

Parent/Carer signature **Date**

Please provide contact details for me to contact you on:

Phone number……

Email ……

Appendix E: Advert for Recruitment

Are you a girl with autism?

Who am I?

My name is Heather Carver, I am a trainee Educational Psychologist and a student at the University of Bristol.

As part of my degree, I am doing a research project to understand what it's like to be a girl and have autism. This is important because a lot of what we know about autism has come from autistic boys, but not girls.

What difference will this project make?

I am hoping that this project will help to make people more aware of what it can be like to be a girl with autism. This could help other girls when they are diagnosed to hear stories about others that have been through it, and it can help professionals when they are working with girls with autism.

Taking part is voluntary

Taking part is voluntary, nothing will happen if you don't want it to.

And you can choose to stop taking part at any point.

What would taking part be like?

I am looking for 4-6 girls with a diagnosis of autism over the age of 12 years who would be happy to talk to me about their experiences of autism – whatever their experience is. I will do my best to make taking part a comfortable and enjoyable experience by offering choices about how we communicate and where we meet.

Taking part will involve a few sessions which you can choose when and where they happen out of some options.

- 'Get to know me' session - The first session will be a chance for us to meet just so you can start to get to know me and we can plan together how you would like to share your experiences.
- Discussion session/s - The next session/s is when we will start to talk about your autism – I will have some things to help us have this conversation. You can choose to have up to 3 of these sessions, but that is up to you, you may only want 1.
- Final session - Then, I would like to meet you again to share with you what I have learnt from the sessions to make sure I've understood your experiences correctly.

If you want more information and/or are interested in taking part, please first talk to your parents or carers if you are under 16 as they will also need to agree; then either you or they can contact me for further information.

My email address is:

My office phone number is:

Appendix F: Information Sheet for Participants

Hi there!

My name's Heather. I'm a Trainee Educational Psychologist which means I visit lots of schools to help support children's learning and wellbeing. I'm also currently a student at the University of Bristol.

I'm really interested in finding out about girls with autism, how they feel about being autistic and what their thoughts and feelings are about it. So I am doing a research project that I want to tell you about so that you can think if you might like to take part.

The study

My main aim is to understand how it feels to be a girl with autism and write this in my thesis (which is a big report!). Another aim is to use the stories I collect to help other girls who have been diagnosed with autism. When it is finished, the research might be published so that it can be read by other professionals to help them to understand what it's like too.

I want to speak to 4–6 girls about their experiences and collect their stories. The number is small so that I can make sure every girl feels listened to and I get all the details right. The first 4-6 girls to want to take part will be selected (others will go on to a waiting list in case anyone drops out).

What you would do

If you want to take part, I would like to meet you a few times:

- Get to know me - The first visit will be a 'get to know me' visit where we can spend some time together and you can ask me any questions you have. I will bring the consent forms for you (and your parents/carers if you're under 16 years old) to sign if you want to take part at the end of this.
- Discussion session/s - After that we can meet between 1 and 3 times to talk about your experiences – how many times is your choice. We will not talk for more than an hour. If it's okay, I will be recording what we talk about in these sessions.
- Final session - Then I would like to meet you a last time to show you the story I've written from what you've told me and check that I've got it right.

If you would like to take part, you and your parent/carer can choose where we meet: at your house, at school (if your school are happy for this) *(the option of school will be deleted for the Support Group Sampling method)*, or in a room at my office (the Educational Psychology Service). If you'd prefer not to talk to me, we can think about other ways we could communicate like writing or drawing – I want to make you feel comfortable and safe to talk to me.

We will be discussing your autism diagnosis, so please think about if you're comfortable with that.

More information

- Your information will be kept confidential (safe and secure). Your transcripts (the type up of what you said) will be stored on the secure University of Bristol server.
- Your anonymised transcripts (the type up with no names) will be stored for 20 years for re-use in future research and learning and can be withdrawn at any time.
- I will anonymise (change all the names of people and places) your information so that you can't be identified.
- You have the choice to not take part at any point with no consequences.
- You have the right to request to withdraw your data at any point.
- During the sessions, if you tell me something that means you or someone else are at risk of harm, I will have to tell someone, but I will let you know if this happens.
- I have been given permission by the University of Bristol, School for Policy Studies, Research Ethics committee to complete this study. This is a group of people who decide if what I would like to do is well thought out and if it will cause any harm or upset.
- When I have finished the project, I will write to you to share what I have found.

Next steps

If you are interested please talk to your parent/carer or your SENCo/Support group staff who can help you with the next step *(-I will delete as appropriate for each sampling method).*

We would then set up a meeting to have a chat and for you to ask me any questions before starting the other sessions on another date.

Heather Carver
Email:
Phone:

If you want to ask further questions about the research to someone that isn't me, or if you have any complaints, please contact my research supervisor:

Dr Robert Green
Email:
Phone:

I look forward to hearing from you. If you have any questions please contact me or ask someone to on your behalf.

Thank you for your time.

Best wishes,
Heather Carver
Trainee Educational Psychologist
Email:
Phone number:

Appendix G: Information Sheet for Parents/Carers

Dear Parent/Carer,

My name is Heather carver and I am a Trainee Educational Psychologist carrying out a piece of research as a doctoral student at the University of Bristol. I am interested in finding out about the experiences of females who have been diagnosed with autism. I am currently on placement within Warwickshire Educational Psychology Service who have approved this research. This research has also been approved by the ethics committee at the University of Bristol and I have an enhanced DBS check which allows me to work with young people.

The study

I am interested in hearing the views and experiences of your daughter and other autistic girls about what they think about autism. I would like to raise awareness and understanding of what it means to be a girl diagnosed with autism. I also hope to inform the support offered to girls after receiving a diagnosis of autism so that it might help them understand their own reactions. Once completed, this research may be published so that it can be read by more professionals to also raise awareness and share the stories I hear.

I would like to speak with between four to six girls about their experiences. The number is small as I will ensure that each story is detailed and representative. The first four to six young people and their parents/carers to consent to take part in the study will be selected to participate. Anyone interested in taking part after the participants have been identified will be contacted if any of this number withdraw.

Your school's SENCo/ Your daughter's support group *(-I will delete as appropriate for each sampling method)* has identified your daughter as someone who may be interested in talking with me.

What would happen?

If your daughter is interested in taking part, I would like to meet her a few times:

- Get to know me - I would start with an initial 'get to know me' visit to give her the chance to meet me informally and ask me any questions. We will discuss how she would like to talk to me in the following sessions (talking/writing/drawing). At the end of this session, if she wants to participate (and you give your permission if she is under 16 years old) we will sort out the consent forms necessary.
- Discussion session/s - My next visits would then focus on understanding her story, this can be from one to three visits -however many she would like. We will not talk for more than an hour and I would record what is talked about in these sessions. Our conversations will be guided by some broad themes that I would like to explore including understanding your daughter's past and present experiences of her autism and how she feels about autism more generally.

- Final session - I would then like meet her one more time to make sure I have captured and understood her experiences correctly.

If your daughter would like to participate and you are happy for her to, together you have the option of deciding where would be best for me to talk with her. This could be at your home when you are available, at her school (if school are happy for this) *(the option of school will be deleted for the Support Group sampling method)* or a private room at the Educational Psychology Service office.

More information

- If your daughter decides not to participate this will not have any impact on any other involvement from the Educational Psychology Service.
- All the data collected will be made anonymous, remain confidential and will be kept in a secure location in line with General Data Protection Regulations.
- Your daughter will have the option to withdraw from the research at any point with no consequences.
- You have the right to request access to your daughter's personal data and the correction or removal of any personally identifiable data at any point.
- If your daughter talks to me about something which I think means she is at risk of harm, I will have to tell someone, but I will let both you and your daughter know if this happens.
- When the study is finished, I will write to you and your daughter to share what I found.

Next steps

If you and your daughter are interested in my study and/or want to ask further questions please contact me either by email or by phone. I can answer your questions and then, if you want to, arrange the initial 'get to know me' visit.

Heather Carver
Email:
Phone:

If you wish to ask further questions about the research to someone other than myself, or if you'd like to make a complaint, please contact my research supervisor:

Dr Robert Green,
Email:
Phone:

Thank you very much for your time. I look forward to hearing from you.

Kind regards,
Heather Carver
Trainee Educational Psychologist
Email:
Phone number:

Appendix H: Narrative Interview Guide

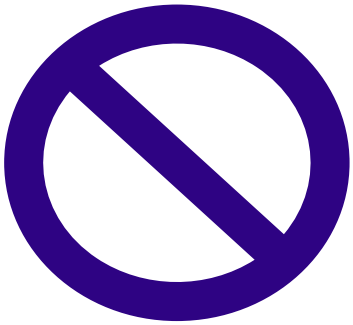
Narrative Interview Guide

- If you're describing yourself to someone, what three things would you tell them?
- Tell me about when you first became aware that you had autism?
- When did you first hear about autism – what did you think of it then?
- Were there any specific experiences that have changed how you feel about your autism?
- Were there any specific people that have changed how you feel about your autism?
- What does having autism mean to you?
- What do other people need to understand?

Appendix I: ‘Stop’, ‘Skip’, ‘Break’ Visual Cards

Please skip

I would like to stop



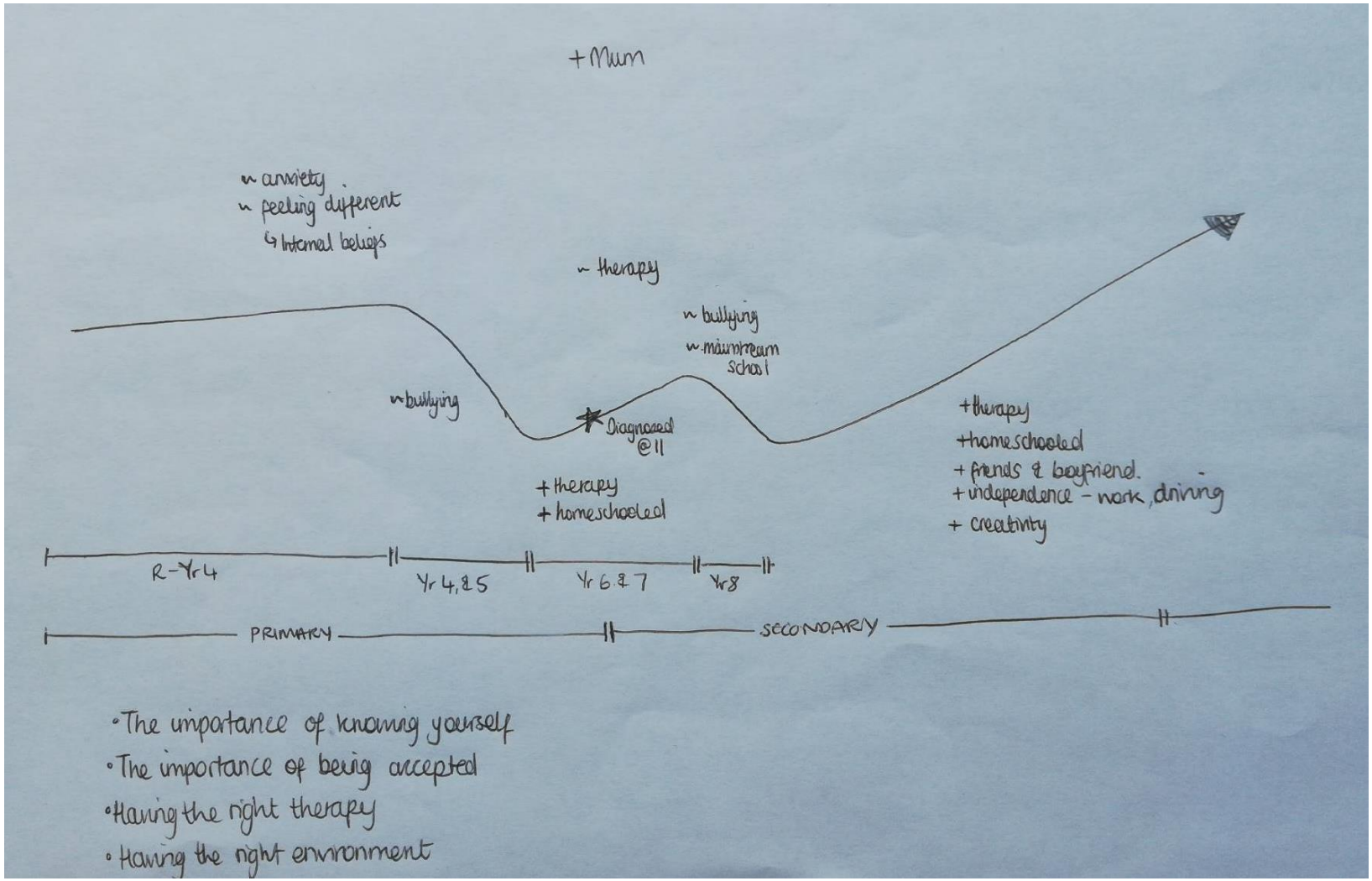
I need a break

Appendix J: Life-Grid

	EARLY YEARS (0-4yrs)	KS1 (5-8yrs)	KS2 (9-11yrs)	KS3 (12-16yrs)
 HOME & FAMILY				
INTERESTS, SPORTS & HOBBIES 				
AUTISM & OTHER DIAGNOSES 				
 SCHOOL				
IMPORTANT RELATIONSHIPS 				

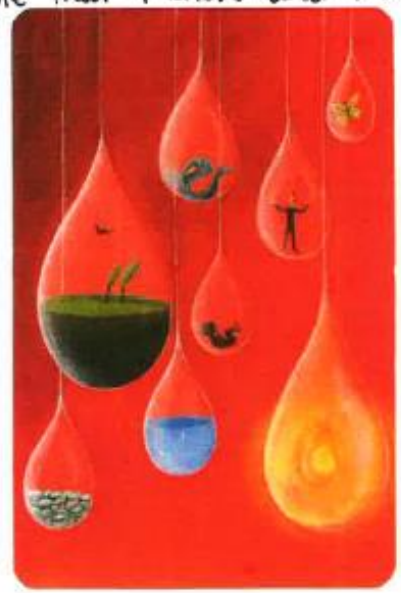
Appendix K: 25 Dixit® Cards

Appendix L: Lauren's Visual Timeline for Analysis and Feedback Session



Appendix M: Olivia's Dixit® Card Feedback

"All of it is in different parts and at home I'm a very different person to when I'm outside or when I'm with people that I know and trust"



"It's different personalities in different spaces"

"I like to be alone most of the time, but I don't mind sitting in a room with another person"

"...there are words in the sky... sometimes it's difficult for me to understand what they're saying or what they mean by it"

Appendix N: Chloe's Quotation Feedback Visual

Appendix O: A Sample of Emily's Working Transcript

Episode	Transcript	Comments
	Key: Underlined words - the sjuzet Highlighted words -sjuzet and fabula Non-edited words - Fabula	Key: - Summarising fabula in normal font - **Emerging themes in bold** - My analysis of sjuzet is in blue font - *Reflections on my influence on the interview and my thoughts at the time are in italics* - **Identity positions in bold grey**
14. diagnosed in January	I: ah I see, and can you tell me about when you were diagnosed with autism, what age were you then? E: erm, it was very recently it was this January I: oh okay right	**Recent diagnosis** 6 months with a diagnosis
15. diagnosis was 'very clarifying'	E: and, we've been trying to use it to help get funding for more help in school er which. To a varying degree of success, erm, it was very clarifying for me because before, I was I was always kind of like (3) saddened by the fact that the therapist I'd been going for a year at that time, had erm, no two years at that time had erm, been saying that I didn't really need one and that it didn't matter and wouldn't change anything because, she was trying to make it sound like no big deal because I'm sure she was thinking that I'd probably label myself with it or something. Erm, which I didn't do it was more of like. a	*'to a varying degree of success' she later shares that she was disappointed in the SENCo who had said she'd have the application completed but hadn't. She said we don't have enough evidence – Emily took this as a personal comment.* "wrong" – deficit-based language

	way to process things, because now I could understand what was wrong with me, whenever so I no longer needed to ask, erm ask in tears why I was feeling this way all the time I: yeah, so it gave you an explanation? E: yeah I: and almost a framework to understand yourself, is that fair? E: [definitively] yes. Yeah that's definitely right	**Diagnosis = help -** 'Trying to use it'- as a currency? **Diagnosis was 'clarifying' –** a way to process things, useful to her "very clarifying" – intensifier of very **Therapist dissuading –** this saddened her **I've had a struggle with it, Searching for an explanation -** Something was wrong. Diagnosis was very emotionally charged for her, she was asking all the time in tears, wanting an explanation – a cry for help? **Being diagnosed** **IP 6 – as an autistic person** Diagnosis was a clarifying explanation?
16. searching for explanations before	I: ah okay, so that's a very recent diagnosis then isn't it. You were saying then that you're therapist then for those two years did she, think that you did have autism then and it's just that she didn't. think a diagnosis would be helpful? Was it something that you'd thought of before…? E: [hesitantly] I don't know what she thought, but I don't think she knew that I had autism. because I was… before I had the diagnosis or even had thought	*Therapist was dissuading* **Typical autistic traits-** other people (she can't remember who) mentioning this to herself and her Mum

	or been told 'oh your daughter' mum I'd been…I have like. Personality traits and things that align with symptoms of being autistic.	
17. thought generalised anxiety disorder and depression	E: I I'd just assumed I had some sort of generalised anxiety disorder or maybe depression. And, erm, I think she was just worried that I was jumping too quickly into like wanting a diagnosis and wanting to understand things I: I see, mhm (2) okay so before that then you were kind of understanding, some of the things that you found more difficult in term of anxiety then and depression? E: yeah, yeah because I'd been on...I'd gone online and like obviously done the things where I just google and ask like what's wrong me… I: yeah, we all do that [laughs] E: yeah and it just…a lot… it came up with the more common like forms of like generalised anxiety disorder not really but it's just feeling of anxiety and so because I had similar feelings to those people who were talking about it online I assumed I was also similar in their diagnosis	**Therapist dissuading** **Searching for an explanation, Anxiety and sadness –** looking for any diagnosis that felt like it would fit, but wanting to so that she could understand herself **IP 7 – as someone with anxiety or depression** Saw similarities with these disorders
18. helpful youth group and mentor	I: mm okay. I see. So you had kind of as a result of that then, you mentioned that you had some therapy, was there anything else that was sort of put in place or any support that you accessed? E: erm, I'm sure I did. [Mum: (charity)] oh yes I was put into a youth group for people of similar like difficulties with general life and stuff [laughs] and we just, we just do like activities and we can access help and it's all run by, or it's all funded by erm, children in need so…	*I find that interesting – goes against the typical idea of autistic individuals needing routine and things to stay the same – becomes a chore!* **'usual' or routine is uncomfortable/ chore, Therapy can be a chore**

	I: aha, and was that helpful? E: yes, it has been helpful and they like provided me with like a mentor who's less of like a weekly therapist because over the time I've struggled to like, get help from a scheduled thing of a weekly therapist because it became more of a chore for me and so it's more of just like having a friend come over who you can talk to and like get those worries of your chest whilst still having a fun time I: mm, that sounds really supportive then, that sounds really positive. And do you still have a mentor now, it sounds like you do… E: yes I: so how long have you had, that sort of help or mentor? E: erm I've had my mentor for. A good, month or two I think [mum: a bit longer than that to be honest] oh maybe a bit more then. I: yeah? And did you have somebody else before or has it only been that that time that you've had that… E: it's only been that time. but I haven't been going to [charity] for very long either. So they got me a mentor pretty quickly I: mmm, and I can tell like by your face that you really do find that supportive, which is lovely E: yeah I do	**Diagnosis = help, Helpful therapy group support – mentor** – has only happened since diagnosis **Self-aware, self-reflective, self-conscious** – laughing at "difficulties with general life", her difficulties are far reaching

	I: so they just. Pop round, is it when you ask them to, or how does that work? E: there is a schedule thing, but it goes by week, so like, it's not the same day, same time every week, it's like. Each time she's here she'll schedule the next one I: I see, yeah, okay. So you find that quite helpful as well that it's not, it's not becoming a chore? E: yeah. Yes. I: mm, mhm, brill.	*Reflecting back her language*
19. autism in school. Need pizzazz	I: Okay. I wondered, erm (2) thinking back to sort of in school, can you, if you're happy to, can you describe to me how your autism and possibly anxiety, and how things effect you in school, how do you find that? E: erm it can vary lesson to lesson. Erm (2) I know particularly for me, RE because of how, this sounds… this is kind of unusual, but the, the sort of, it's very text book definition of a classroom our RE class, and, there's nothing different about it, and so, just like it makes me kind of feel uncomfortable that's it's just like the most. [sigh] *usual* of classrooms, whereas with other classes like science the desks are different and like with media I just enjoy that one on its own I: mmm. So RE you find hard because it's… E: so usual	*Physical environment is so important to her* **Difference/change is good , 'Usual' or routine is uncomfortable/ chore –** sigh and emphasis on usual indicates that she gets bored of it **Atmosphere of school feel wrong –** because environment isn't right for her, she needs 'pizzazz' quite a dramatized word to choose **IP 5 – as a student** Disliking 'usual' classrooms

	I: okay! Yeah E: I need difference and like (2) pizzazz I: yeah? And that's fair enough and RE doesn't give you that to you [laughs] E: [smiling] yeah I: is that the topic or the teacher or… E: no it's not the topic it's the classroom I: right, so the environment then, the physical tables and chairs and… E: yeah	Needing pizzazz in her environment
20. other children misbehaving is hard	I: okay, aha. How else does your sort of autism and anxiety effect you in school? Or how *has* it in the past? E: erm, sometimes I'll need…I'll just be like most of the time it's the other students, because for me I have quite a strong sense of justice so when I hear people misbehaving or just talking in class and then I don't see the teacher immediately running across from the child that they're helping to send them outside with a detention then I get erm upset,	**Other students misbehaving, Anxiety and sadness, Vulnerability** – she can be very affected by those around her even when not doing anything directly to her "strong sense of justice" – a mature way to describe this **IP 5 – as a student** Don't like other students messing around

21. time out card	E: and so sometimes I'll use, I've been given a time out card so that I can just go out of a classroom and just show that so that I don't need to like put my hand up and ask and I'll just go out for a breather I: yeah, mm, so when other students are kind of messing about you sometimes have to use your time out card? E: yeah I: and does that help you then, can you calm and come back in? E: yes I can I: yeah. That sounds really good then. And are teachers, okay with you using that? E: yeah they've all been told that I'm allowed to use it I: that's fantastic, really good. And who was it that gave you the time out card then that started that? E: erm there is a, leader of the SEND…erm I: mmhm, the SENCo maybe? E: SENDCo yes. [mum: I asked for it] yes [laughs] mum was the one who came up with the idea but it was our SENDCo who got it like to be a thing I: aha okay, but mum had to sort of approach them and, ask for it then, yeah	*Sounds like school are informing all teachers of the strategies Emily needs which is good for consistency* **School support: Time out card, SENDCo, Mum's influence** – but Mum has to make time out card suggestion, but SENDCo actioned it She couldn't remember the SENDCo's job title

22. review meetings in school	E: yeah. Because every few months or so we'll go into like a meeting where we'll discuss new ideas and new ways that we could help me get back into being comfortable in school every day I: mm, okay. And how do you find those meetings? E: err, I find them less helpful than the adults in the er meetings do. Perhaps because I'm a little more…er I have little lower an opinion of school than the adults do I: okay	*Interesting that she finds them less helpful – it should be about her and for her. But also good that she's there and is involved* **Just don't like school** **Review meetings aren't helpful** **IP 8 – as a teenager** Separate to the adults
23. just don't like the school	E: because it just isn't….I just don't really like the school that much, it's nothing really that they're doing, it's more the area just makes me a bit. uncomfortable I: the area do you mean within school or do you mean outside of school? E: the atmosphere within school is so much *darker* than when I'm out of school I: I see, ah okay	**Just don't like school, Dark atmosphere of school** – doesn't seem hopeful that there's a solution **IP 5 – as a student** Feeling uncomfortable at school
24. I'm not the general public, I need more personalised school	E: and so I get….also I used to be kind of, a lot more. annoyed that it was compulsory because I didn't like [laughs] because I didn't want to be controlled by someone who barely knew me because they just made the law. thinking for the general public but I'm not part of the gen- well I am, but like. I'm not as easy to cater to as the general public	**Self-aware, self-reflective, self-conscious-** *Wider annoyance with the whole school system.* **Environment and atmosphere feel wrong, Feeling depersonalised, I'm not the**

	I: I see yeah. That's fair enough, so you feel like maybe the school environment isn't…what would the word be…individualised enough? E: it's not personalised enough for me (2) a common joke that me and my friends have because we have similar opinions on that is that the headmistress of the school, although this is ludicrous of course, but a common joke we have is that she refers to students by number [laughs] because it kind of gets across our point without well without being too kind of dark about it	**stereotype/ general public -** School isn't personalised, Separating herself from the general public **Close friends in secondary –** having in- jokes. She's *conscious to make sure I know it is a joke and she doesn't actually do this*
25. it's a big school	I: aha. I see yeah. Is it quite a big school? E: erm, for the UK yeah it's, I think it's 1500 students I: right and it's year 7 through…does it have a sixth form? E: year 7 though to 13 I think I: yeah? Yeah okay, so the head teacher does have a lot of students there, but you find, you at least feel a bit like you're just a number in that school? E: yes	*Summarising and reflecting back her analogy* **Feeling depersonalised –** she's just number **IP 5 – as a student** Feeling depersonalised and overlooked in school
26. on a reduced timetable	I: aha, I see. So at the moment then how much are you in school, are you on a reduced timetable, is that right? E: erm we're not officially…we're officially on a reduced timetable but we've kind of reduced even that cuz. But like…we just find it difficult to kind of stick	*Who's the we? I think she means herself and Mum?* *Conscious to explain for me what a vertical tutor group is*

	to it, like I'll still go in but I just won't go in at the right times that it says on this timetable I: and why's that? E: erm, some lessons as I said are more difficult than others and I'll prefer to go to the ones that I can do, which right now have been English history, maths media (2) and the others I'm struggling with a little bit I: and do those lessons on your timetable, do they tend to come together or is it that you go in come out and go in again on the same day? E: er, English and history come together quite a lot. Erm, like on Mondays' for the last two lessons I have maths and then media so I go for the last two lessons and a lunch and a vertical tutor group which is just like a tutor group but with varying years I: with the different years in right? E: erm so I go in for a good three hours and then Tuesdays and Wednesdays is an English and a history. Usually it's a two hour period but sometimes it can be more than that depending on. how I feel, and other factors I: yeah? So it kind of changes day by day? E: yes.	**Reduced timetable –** school strategy to help her **IP 5 – as a student** Part time attendance to make it easier

Appendix P: Maddison's Categorical-Content Analysis Tables

Research Question 1

Over-arching theme	Narrative theme	Episodes within transcript
My autism	Autism in school	12, 14, 28,29, 30, 31, 33, 36, 37
	Having a different perspective	4, 29, 30, 38, 47, 49,
	Feeling different	12, 14, 43, 44, 53
	Not understanding friendships	11, 14, 15, 18
	Need logic/ questioning the norm	12, 30, 31, 47
	Not the only one	33, 36, 43, 44
	Social masking/ copying people	18, 49
	It's just there	20
	Didn't know a lot about it before	21
	Need own time	55
Reflections on autism more broadly	Potential isolation of diagnosis	43, 44
	In group/ out group	47
	Diversity of autism	48
	Power of stereotypes	48
Autism diagnostic process	Mum's involvement	17, 18, 19
	Recent diagnosis	16
	Long process	18
	Didn't make sense	18
	Not surprised	19
	Not a sad thing	19

Research Question 2

Over-arching theme	Narrative theme	Episodes within transcript
Primary school friendships	Vulnerability?	9, 11, 14
	Nobody close	11, 14, 15
	Lack of belonging	14, 15
	Mean girl	9
	Can make friends out of school	13
Secondary school friendships	Sense of belonging	4, 5, 6, 34, 35
	Friends/teachers knowing	32, 33, 37
	Open minded friends	4, 5
	More friends	5, 34
	Started alone	8, 10
School support	Learning passport	37, 38, 39, 42
	SENCo lady	37, 40, 41, 42
	Teachers making an effort	37, 38, 39
	Weekly check-ins	41, 42
Recreational activities/interests	YouTube	22, 24, 25, 26
	Activities	50, 51, 52, 53
	Debate club	27, 53